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TITLE: Factors Affecting African American Women's Participation  
in Breast Cancer Screening Programs: A Qualitative Study  
of Uninsured Low Income Women

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## **Introduction**

Breast cancer screening programs offer the greatest promise for early detection but rates of participation in these programs have been extremely disappointing for low-income African American (AA) women. Although the Breast & Cervical Health Program of the U.S. has been successful in enrolling thousands of low income AA women since its inception, hundreds of these women in Washington state have declined a free screening mammogram, despite diligent outreach by community workers and despite offering them access to free screening services. The purpose of this Idea Grant was to discover and elaborate, using both face-to-face and focus group interviews, the beliefs and attitudes toward breast cancer and screening that are held by fiscally challenged African American women. Our assumption was that such beliefs and attitudes affected the women's decision to participate or not participate in a free breast cancer screening program. This completed study involved 2 phases. Phase 1 involved contacting a population database of fiscally challenged African American women for individual interviews and Phase 2 involved focus groups in which women from Phase 1 served as expert reviewers for the results obtained from analyzing Phase 1 interview data. Study results, reported below, resulted in the elaboration of an extensive and complex set of beliefs about breast cancer and related services that challenge the validity of the current media and program materials that are used to encourage African American women to participate in breast cancer screening services.

## **Body of Final Report**

The approved Scope of Work (SOW) and its 34 related operational tasks have now been completed for this Idea Grant. The objectives for the SOW are listed in Figure 1; Figure 2 contains a summary of the status of the approved tasks.

### **Figure 1: Objectives of Approved Scope of Work for Phase 1 and 2**

1. To conduct and audio-tape record case intensive interviews with African American fiscally challenged women who are drawn from a population data base of eligible women who were referred into but did not enroll in the breast cancer screening program in the Breast and Cervical Health Program in Seattle King County, Washington state. [Phase 1 activities]
2. To use technical methods to inductively code and content analyze the transcribed audiotapes from the interviews in order to identify factors associated with non-attendance in free breast cancer screening programs. [Phase 1 and 2 activities]
3. To conduct focus groups involving African American women from the same population data base of fiscally challenged women in order to check the accuracy and thoroughness of the factors associated with non-participation that were identified from the coded interview data. [Phase 2 activities.]

### **Figure 2: Completed Tasks in Approved Statement of Work**

Tasks 1-17	Months 1-12	Completed
Task 18	Months 13-24	Completed
Task 19	Months 13-24	Completed
Task 20	Month 18	Completed
Task 21	Month 18	Completed
Task 22	Month 24	Completed
Task 23	Month 24	Completed
Task 24	Month 24	Completed
Task 25	Month 24	Completed
Tasks 26-34	Months 25-36	Completed

Phases 1 and 2 are discussed below, followed by the scientific results that emanated from an analysis of the data from the individual and focus group interviews.

### **Phase 1: Elicitation Interviews of Women in Population Data Base**

An initial confidential population database was downloaded to a recruitment intermediary. Detailed spreadsheets were then maintained by the intermediary that enabled us to track the total population of potential study participants, including contact attempts, rate of

outreach, enrollment, accrual and refusals. Detailed notes were kept on reasons for refusal. A minimum of 6 contact attempts; some received 10 contact attempts.

The initial population database consisted of 685 eligible women. Of these, 28 were immediately ruled out because no phone number was available for them. Of the remaining 657 women, 290 women (44%) had non-viable phone numbers [wrong phone numbers and out-of-service numbers]. Of the 559 women with potentially viable phone numbers, 175 women (31%) were successfully contacted by the intermediary.

Of the 175 women contacted, 26 women explicitly declined the intermediary's invitation to participate. This small number involved the ONLY women who explicitly refused to participate in this study based on phone contact. This represents an initial refusal rate of only 15% (26/175).

Of the 175 contacted women, another 91 were screened out as ineligible by the intermediary based on data obtained during the phone contact. The most frequently cited reasons for ineligibility were the woman's claim that either she had not refused a free mammogram or that she had obtained a mammogram from another source during the time of the outreach by the BCHP outreach worker. This high rate of ineligibility raises questions about three things: the completeness of information stored in the population data base from which this team drew the study sample; recall error; or a self-enhancement or social desirability bias in the woman's response.

A total of 192 additional women had viable phone numbers but, despite repeated contact attempts at different times and on different days, only an answering machine, not a "live" voice answered the call. This represents 52% of the women with viable phone numbers.

A total of 58 women (58/175: 33%) verbally agreed to have the intermediary give their name and phone number to a study team interviewer. Of these 58 women, 9 either declined to be interviewed after the interviewer contacted them to establish an appointment or were screened out by the interviewer as ineligible.

This population data base was updated two times during Years 1-3 by Dr. Lin Song, the epidemiologist and Co-PI of this grant. Additional women were identified who chose to not obtain a screening mammogram after being outreached by a community outreach worker. These additional women were then contacted by the study intermediary, after which they were entered into the population data base to be contacted by the study intermediary. [We have retained the detailed records of the code numbers and records of attempts of contact, along with times and days of contact for each eligible woman in the population data base.]

### **Phase 2: Focus Group Study**

Phase 2 has been completed. Focus groups were conducted with African American women who had participated in a prior Phase 1 interview and who had consented to be re-contacted for participation in a Phase 2 focus group.

The purposes of these focus groups was to examine the credibility of study results obtained from Phase 1 interviews as well as to further elaborate on those or new beliefs. See Figure 3 below for the questions that were used in the focus groups.

### Figure 3: Phase 2 Focus Group Questions

1. Even when women knew the value and benefits of getting a mammogram, some chose to not get it when they had no breast symptoms. What would you say to that?
2. Some women told us that getting a mammogram is the same thing as saying they have breast cancer. What do you think about that?
3. Women have told us that early screening and detection of breast cancer does nothing for the woman; she will die from the cancer anyway. What do you think about that?
4. Some women told us that there was no reason to get a mammogram because if the cancer is there, it won't help to get the mammogram. What are your thoughts about this?
5. Some *other* women told us that finding breast cancer early is the best way to get it cured. These same women also decided to not have a mammogram. What do you think?
6. Women told us they'd rather be dead than to have breast cancer. What would you say about that?
7. Some women told us they would never be with a man again if they got breast cancer. What do you say to that?
8. Women told us that a woman should not have a mammogram because a mammogram only causes problems. What are your thoughts about that?
9. Some women told us that they know their own body and when they do or do not need a mammogram. What do you think?
10. Some women told us that they have been very poorly treated- if not mistreated- when they got a mammogram in the past. What has been your experience?
11. What else would you want us to know about mammograms or breast cancer that you have not yet had an opportunity to tell us?

After signed consent, the focus groups were AV-tape recorded, transcribed verbatim, and coded using the same inductive coding strategy that had been used with the Phase 2 interviews. There were three sets of results: further elaboration of the main results from Phase 1, new results that were documented for the first time during the focus group interviews, and recommendations for needed changes or new directions of services for African American women participating in a breast cancer screening program.

Women in the focus groups did not disconfirm any of the results that we had identified from the Phase 1 interviews, although we had designed the focus group questions to encourage *disconfirmation* of what were among the most controversial of our Phase 1 study results. Stated

in another way, the focus group questions were purposefully developed to disconfirm what we discovered, not to confirm what we found. Instead of disconfirmation, women in the focus groups often elaborated on the result with additional personal examples or with clarifying or explanatory text.

In 2003, the research team was granted a 1-year no-cost extension to complete the coding of all the Phase 1 interviews and to conduct all the activities for the focus groups in Phase 2. All tasks under the approved Scope of Work for the 1-year extension have now been completed. In fact, the research team has *exceeded the goals* of the proposed approved time line; see Figure 4. Specifically, not only did we generate professional papers from study results, we wrote and submitted a new grant that used results obtained from the completed DOD grant to write the new grant whose purpose is to develop a set of new educational materials for fiscally challenged African American women, their community outreach workers, and the health care providers who medically serve these women. The new grant has now been merititoriously reviewed and has just received funding by the Susan G. Komen Foundation, Puget Sound Affiliate.

#### **Figure 4: Approved Activities for 1-Year No-Cost Extension**

##### **COMPLETED: August-December , 2003**

Complete coding of interview data  
Construct questions to use for Phase II Focus Groups  
Submit and receive human subjects approval for Phase 2 focus group study

##### **COMPLETED: January-April, 2004**

Identify/ contact women to participate in Phase 2 focus groups  
Conduct focus groups  
Transcribe data from focus groups  
Code focus group data

##### **COMPLETED: May-August, 2004**

Triangulate focus group data with prior data obtained from Phase 1 interview study.  
Submit professional publication(s) on study results.  
Present study results, including programmatic recommendations, to Breast & Cervical Health Program leadership/administration, Washington  
Present study results to other policy and program boards<sup>1</sup>  
Complete final report to Department of Defense.

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<sup>1</sup>We have now presented our study findings to 2 local boards [Susan G. Komen Breast Cancer Foundation, Puget Sound Affiliate; Community Partners' Board, Seattle King Department of Public Health], 1 state board [Breast & Cervical Health Program, Washington State Health Department], and 1 national professional conference.

## **Study Results from Phases 1 and 2**

Results to be reported below represent a *triangulation and integration* of results obtained from the analysis of both Phase 1 and 2 interviews. In addition, multiple research papers have been written, are under review, and are in-process of submission by the study team. In the Appendix, see an example of a paper-under-review by Taber, Lewis, & Phillips-Angeles. A complete list of the publications under review and under development is in the Reportable Outcomes section of this Final Report.

The organizing framework to report the triangulated and integrated results are the 10 assumptions that form the basis for the Breast & Cervical Health Program (BCHP). See Figure 5. Results obtained from the interviews from Phases 1 and 2 refute virtually all of these assumptions. Stated in other terms, the attitudes and beliefs about breast cancer and screening of fiscally challenged African American women who participated in the completed study are inconsistent with the assumptions that form the basis for the existing Breast & Cervical Health Program.

### **Figure 5: Assumptions of the Breast & Cervical Health Program<sup>2</sup>**

- Assumption 1:** Mammograms are effective methods for detecting breast cancer.
- Assumption 2:** Screening mammograms have documented health benefits.
- Assumption 3:** Screening mammograms can only benefit the woman.
- Assumption 4:** A mammogram is a consumer-friendly experience.
- Assumption 5:** Mammograms involve brief, slight compression.
- Assumption 6:** Treatment for breast cancer reduces morbidity and mortality.
- Assumption 7:** Breast cancer is a potentially curable disease.
- Assumption 8:** A diagnostic biopsy is a beneficial part of early diagnosis.
- Assumption 9 :**Mammograms are more effective than breast self exam.
- Assumption 10:** Risk factor education is key to adherence to screening guidelines.

<sup>2</sup> These assumptions were identified by the current study team.

Results that are reported next are organized under these assumptions. The *italicized text* in the text below are the verbatim words the women stated in their interview data; they are not the words of the study team.

**Assumption 1: Mammograms are effective methods for detecting breast cancer.**

Contrary to the media and outreach messages, mammograms were not consistently viewed as effective methods for the detecting breast cancer. Study participants claimed that mammograms were suspect and did not engender confidence in the women. Mammograms were not reliable. They were known to *miss things*, meaning they were ineffective, insufficient, missed *some of the lumps* and *sometimes they're not conclusive*.

Some women questioned the accuracy of mammograms or thought that mammograms were not needed when a woman was rarely sick, therefore there's no need to get checked often.

Mammograms were also suspect because they are viewed as extensions of the White man's control of the African American's body. Like the Tuskegee experiments, breast cancer screening programs for African American women may be the white person's way of inflicting harm, not good, on the women.

**Assumption 2: Screening mammograms have known health benefits for women.**

Public campaigns tout the value of a mammogram as the single most effective method to detect breast cancer, enabling providers to diagnose it at its earliest stages, thereby maximizing the health benefits to women. However, many of the study participants did not think that mammograms benefited them. Some women believed that women with no breast symptoms only *created problems* for themselves when they had a mammogram. *Why fix something that is not broken?* one participant asked. According to some study participants,

when a woman had no breast symptoms, she did not need a mammogram. For some women, there were no known benefits of a mammogram to a woman's health when she was symptom free.

**Assumption 3: Mammograms can only benefit the woman.**

Media and programmatic messages depict mammograms as a helpful screening technology with no negative outcomes. That assumption was not supported by many of the study participants. Mammograms were not viewed as neutral screening or diagnostic procedures. Instead, for study participants, ***mammograms created problems***. They exposed the woman to ***dangerous levels of radiation*** that she knew were not good for her. ***I feel like the radiation is going too deep into the body instead of just going through the breast to initially take the picture.***

Mammograms, in the view of some of the study participants, increased the woman's probability of having breast cancer or they resulted in a diagnostic biopsy that put the woman at risk for ***introducing or spreading cancer*** in her body. See Assumption 8 below for text on the negative consequences of a diagnostic biopsy.

There was evidence of an even more complex and higher level personal threat associated with a mammogram in the beliefs of study participants. ***The mammogram exposes a woman to the risk of finding or causing cancer.*** Mammograms might find breast cancer, and that news would be devastating. Here are example words from the women: ***My biggest fear, than when I do go and have one [mammogram], I might get some harsh news.***

Additionally, ***Since I've never been checked for it [br ca], that I would find out I have it.*** One woman declared that she would be ***particularly devastated*** if a mammogram detected that she had breast cancer.

#### **Assumption 4: A mammogram is a consumer-friendly experience.**

Media messages suggest that having a screening mammogram is easy; at most, it requires that a woman takes time out of her day to both schedule and complete a screening appointment. For study participants, the entire experience of having a screening mammogram was much more complex and exacting than what is portrayed in the media. For many women, having a mammogram was fraught with open manholes: it was not a matter of where or when the woman would be tripped up or fall, it was just a matter of when something traumatic would happen to her.

Mammograms were interpersonally difficult experiences for some of the study participants. The difficulty began, for some, when they detected a certain kind of negative “attitude” from staff at the screening facility. One woman commented about this attitude from providers in this way: *‘You have to just be glad that I’m doing it,’ that’s the kind of attitude they had.* Women also commented on the quality of the medical care they received from the physicians. As one woman said, *when you go for a mammogram, they are supposed to lay you down and they’re supposed to feel, too. But they don’t—they do not! They do not, they don’t do it like that anymore. I do my own exam, and my doctor—all they do is the mammogram....when I go for a mammogram every year: “OK, go look it over ... ok, everything’s fine ... you can go.”* ***That’s wrong; that’s wrong.***

Another woman shared, *I think in all the years of getting medical care, I don’t think I’ve really ever had a good physician, you know. And I’ve had women. Somebody that really cares and goes beyond the surface.*

Sometimes poor medical care was explicitly associated by the women to their challenged fiscal situation. As one woman explained, *So you make a little money but that doesn't mean that you should have bad manners and that you're god.*

The women were distressed, too, by the response of the technician when the women disrobed for the procedure. Many women reported that the technician gawked at the size or asymmetry of the woman's breasts. Some study participants also reported that they had personal difficulty in disrobing because they were embarrassed about the size of their body.

Women talked about the radiology technicians who judged the shape, size or asymmetry of the women's breasts. They talked about the clinic receptionists having a negative, judgmental *attitude* toward the women because they were getting free services. The study participants said that they did not want *no attitude from them [sic]!*

Women also commented about feeling rushed in and out of the clinical breast exam that accompanied the screening mammogram; their experiences and words were negative, leading them to further distrust providers. Here are example statements from women in their own words.

*When she handled my breast it was almost like machinery or something...They're worried about doing a good job but you also you're working on a human being... everything is like mass production, mass this, fast, fast, fast . Sometimes in your, your medical [sic] you feel like you're on a slab and just going down the assembly line.*

Media messages about mammograms focus on the efficiency of the procedure, not the encounter with the radiation technician. For study participants, their encounter with a radiation technician was a source of distress and concern. This distress related to the technician's skill level, the failure of the technician to treat the woman with respect, the technician's ways of rushing the woman through the procedure more like she was a number than a real person; the

amount of pressure and pain they caused; and the lack of interaction or explanation that was offered to the woman by the radiation technician. Painful repeat mammograms, required because the mammogram was not up to standard, were also a source of distress. As one woman offered, *Boy, when they don't get it right the first time...and they miss something...and they want to do it again and again and again and again...They say, 'Miss Becky, we missed it. We didn't get it right. We have to do it again.'*

**Assumption 5: Mammograms involve brief, slight compression.**

Health care providers and health educators think of mammograms as helpful and efficient methods to detect breast cancer that involve brief, slight compression. That was not the dominant view of the procedure by study participants. For them, mammograms were both physically difficult and interpersonally distressing examinations that left them feeling pain and distress long after the mammogram appointment. Pain for the women was both physical and personal.

Physical pain came from the procedure itself. They described the pain as "pinching," "mashing," "squeezing like a pancake," and "smashed." One woman likened the pain to the pain associated with having a baby. In her words: *Psychologically I'm almost like this, give me a valium or give me a shot or something before I go in there because I'm getting very frightened of that pain. It's like you're having a baby, you know, it hurts to have a baby...if you can just put it off, I'll wait another few years before I'm gonna have another baby [that is, have another mammogram] because I know the pain's coming.*

Some women claimed they were so tender after a mammogram that they could not have sex or even brush up against their own breasts because of the tenderness. Women reported, too, that they developed bruises from the mammogram. One woman claimed having a mammogram was like having your finger shut in a car door. These were her words: *The machine's gotta do*

*something; the machine does not know the pain it's inflicting. It's just trying to get this asymmetric breast to contour like a pancake and it's just not happening. But it manages to flatten it out with such pain. It's like closing your finger in a car door, how long do you want to keep your finger in a car door. And you're gonna take your second finger and put it in another car door? You know what you just went through.*

Although a mammogram requires compression and temporary discomfort, study participants described their personal level of pain and discomfort from the procedure in more extreme terms. *They torture you just to do a picture.* Women used words like *painful, vice, squeezing device,* They described the compression is often severe terms. *Everything is all stretched and squished.* This stretching and squishing is thought to have negative consequences. *I know that when you're stretching that skin, you're breaking down some cells and I just think, okay, now we got to get them back together.*

The women's images of the compression procedure were negative. *When they put it in those, the whatever that machine is and they screw that, it feels like, uh, reminds me of the medieval vice that they put people in.* In another example, a woman commented that having a mammogram was like getting your finger smashed in a car door.

The mammogram was also interpersonally difficult for many of the women. One woman said it this way; she wanted them to treat women *like we're human beings, and not like we're grazing on grass.*

#### **Assumption 6: Treatment for early stage disease reduces morbidity and mortality.**

Medical evidence is that treatment for early stage disease is the most effective way to reduce morbidity and mortality from breast cancer. Despite this medical fact, study participants did not laud the value of treatment nor did they consistently link treatment with reduced

morbidity or mortality. For many, the converse was true: they thought that early treatment for breast cancer resulted in high psychosocial morbidity. They specifically doubted treatment efficacy in reducing mortality and few women reported any value to chemotherapy or surgery.

Surgery for breast cancer came at a high cost to the woman's sense of self. They claimed that a mastectomy maimed, distorted, or permanently damaged the woman's body. This damage went far beyond the surgical scar. Changes in their bodies from the surgery would cost them dearly. Disfiguring surgery caused them to lose their attractiveness to men and made them think that no man would ever want to be with them again. Some said they would rather die or be dead than to have surgery for breast cancer. In the words of one woman: ***I could see where someone who had lost their breast wouldn't feel normal anymore, you know, like a woman.***

Overall, this meant there was a no win-win situation for many of the study participants when they had a screening mammogram that detected breast cancer early. The disease was caught early, the women did not believe in a cure. If the disease resulted in a mastectomy, they had two responses: the disease would spread because of the biopsy or surgery itself or they would feel disfigured and less of a woman. If they got treatment from chemotherapy, they thought the chemotherapy would do bad things to their body. Even hair loss would be unbearable for some.

**Assumption 7: Breast cancer is a potentially curable disease.**

Media messages emphasize that breast cancer is a potentially curable disease. Hopeful outcomes, including a high probability of a lifetime cure, are lauded in media campaigns and educational materials. These positive messages were not a consistent part of the frame of reference for study participants.

Women feared mortality from breast cancer; in the words of the women: *I just know that it [br ca] will take your life if you have it...because I do worry about death. Breast cancer could kill me.*

Although some argued the importance of early detection, others also believed that there was really no cure for the disease, no matter when it was detected. In short, the diagnosis of breast cancer, even early stage breast cancer, became a signal for death, not hope for recovery, for many women. Here are the words of one woman who expressed her view that breast cancer was like having AIDS: *Cancer is a disease that eats you from the inside. Um, it's very less likely to control or to eradicate, even though they have a lot of chemotherapy. But even though it goes into remission, it's just something that lays dormant 'til (sic) it seem to come back, and ki-, constantly haunt you. I've had too many friends, and, uh, other relatives who have died of different forms of cancers. And it just, it's, like, to me, it's like AIDS – something that's incurable. You know, they just put it on hold for a little while. But it's incurable. It's a ugly disease.*

Study participants expressed skepticism about the outcomes of cancer treatment and said: *they don't have a cure for cancer, no type of cancer.*

Some of the women's prior personal experiences with someone with cancer involved persons who suffered after being diagnosed with breast cancer or died a difficult death (Phillips-Angeles, Lewis & Taber, Under review; editorial decision pending). [See Appendix for major results section of this manuscript for further details.] Friends and relatives who died from the cancer were among the common memories women discussed. Here are the words of one woman who supported a close friend with breast cancer:

*[woman sighs] Hmmm. Very traumatic. Um, mostly just very traumatic. Uh, very heartfelt, um, a lot of prayers, a lot of consoling, a lot more prayers, and a lot more consoling. Um, it, it takes a lot of, out of you mentally. You know, and then it pull-, tolls on you physically 'cause (sic) you're givin' (sic) the person a lot of your time, you know, and your energy. And, uh, being, that's friendship. That's, part, part of friendship, you know. It just really takes a toll on you emotionally. 'Specially (sic) when you have a friend you've known quite a bit of your life, and they have to lose a breast or both breasts, you know. Mmhmm. And the emptiness they feel is you're sharing it with them. Mmhmm. Yeah.*

*As one woman stated it, the Lord may just prolong your life to give you a little longer to live you know, but it [the cancer] eventually comes back and gets you and kills you. So when you get cancer you're through.*

**Assumption 8: A diagnostic biopsy is a beneficial part of early diagnosis.**

A diagnostic biopsy is a necessary component for the diagnosis of breast cancer; it allows the physician to determine the presence of cancer and often the cell type and cell activity. It is one of the essential parts in the linear medical model of differential diagnosis and informed treatment for breast cancer. This is how a medical care providers view a diagnostic biopsy. This was not the view of some of the study participants. For them, the biopsy created problems in one of 2 ways: the procedure exposed the woman to the introduction of breast cancer cells that are in the air [sic] or it spreads the cancer that might exist in the breast to other parts of the body. Here are example quotes from the study participants: *Once you open that area up [the breast], wherever the cancer's located, it just send [sic] it throughout your body. When they open you up and cut on you, I think it's freeing the cancer.* Finally, *If you had never let them cut you, you would never ever got air, and then it wouldn't be bad.*

**Assumption 9: Mammograms are more effective than breast self exam.**

Every message about screening mammograms argues the comparative effectiveness of a mammogram over a woman's breast self exam. Drug companies have spent substantial funds in full-page advertisements arguing that point in lay magazines, including the *Scientific American*.

Women in the current study argued differently, offering examples of evidence that told them they knew their own body better than a mammogram. *The one [mammogram] I had prior to me feeling....finding it myself...there was nothing there. There was nothing there. I looked at it [mammogram] myself, and I thought there was nothing there.*

Women thought that breast cancer could be *overlooked by that machine* and the cancer *could be overlooked*. This view is upheld by things they hear from others: *some critics say it's [mammogram] good; some critics say it's not.*

**Assumption 10: Risk factor education is key to screening adherence.**

Media and educational messages about risk factors for breast cancer are thought to positively influence compliance with breast cancer screening. Results from the current study suggest instead that each woman has her own personal model of risk factors that are not only unique to her, but are not consistent with known biological facts. Her view of her own risk factors, not the results from biological studies, guide her own screening practices. Women believe, for example, that you will not get breast cancer if it has never been diagnosed in a family member. In the words of the women: *I really don't have any fears about breast cancer.*

*Nobody in my family ever had it...I'll never get it.* Additionally, *I was led to believe that it wasn't important for me to have regular screening because it doesn't run in my family.*

Perceived low personal risk for breast cancer would further push them away from choosing a screening mammogram; for them, breast cancer is a non-issue [analogous to the first stage in the Precaution Adoption Model of health-related behavior. This is much more than the women believing they are not susceptible to the disease, as would be suggested by the Health Belief. It instead means that breast cancer is not even on their personal radar screen as a relevant issue.

### **Discussion of Results**

Breast cancer screening programs are based on a set of finite assumptions about the benefits and effectiveness of both screening mammograms as well as the early diagnosis of breast cancer. Results from interviews obtained from a community sample of fiscally challenged and primarily uninsured or under-insured African American women challenge the validity of these assumptions. Study results instead revealed that the beliefs and perceptions of study participants did confirm the validity of these assumptions.

In an attempt to actively protect their own health and self-defend against an unreliable technology and related circumstances (interpersonally inappropriate medical personnel; damage-causing biopsy, among others), women chose to not obtain a free screening mammogram or an interval-appropriate repeat screening mammogram.

Women in the study decided, within an informed frame of reference, when they did or did not think they were personally at risk for breast cancer. They told us that they knew their own bodies and had historical personal experiences that confirmed this self-knowledge. They

claimed to know about their own body even above and beyond the knowledge of their medical providers.

Women who chose to not have a screening mammogram were active agents, not passive agents, in their own self-care. They acted in ways that protected themselves against noxious radiation, unnecessary exposure to a breast biopsy when they had no breast symptoms, and when it was thought that the biopsy itself would either introduce cancer into or spread cancer through their bodies. Even though some of these beliefs and perceptions were not convergent with the best evidence in medical and biological sciences, none-the-less these beliefs were firmly grounded in the women's personal experiences and views.

In both the interviews and, in particular, in data obtained in the focus groups, there was a recurring and dominant theme of mistrust and distrust for medical providers. White doctors, in the reports of the women, were not to be automatically trusted. There were unremitting feelings that the physician was not giving the African American women the best medical care, was often rushing her into and out of the examining room, and short-changed her, offering perfunctory and ill-conducted clinical exams. Linked with the women's reports and awareness of the experiments that were conducted against African Americans in the Tuskegee Institute, women expressed feelings of mistrust and distrust of physicians.

Even though study participants were active agents for their own health, they were essentially damned if they did and damned if they didn't have a mammogram. By having a mammogram, they were giving into the possibility or reality that they have or might be at risk for breast cancer. With its link to death and suffering, a screening mammogram says to themselves and the world, I am at risk to be suffering and dying from the disease. Both the suffering and the dying hold intolerable prospects for the women. By not having a mammogram, the women are

medically and epidemiologically putting themselves into a high risk place: at being diagnosed with advanced stage disease.

Breast symptoms figured prominently in the women's view of their risk. In their view, the absence of breast symptoms meant that a woman did not need a mammogram. This is unfortunate; medically speaking, breast symptoms could herald the presence of breast cancer, including advanced breast cancer. Waiting until breast symptoms appeared might be too late to detect the disease at its earliest [in situ or local] stage.

Women are their own best self-protectors. They have learned that others do not care nor are others their advocates or benefactors. At both a societal and recent interpersonal level, others, including radiation technicians [and receptionists?], treat them with disrespect or judgmentally. All these experiences have reinforced their need to be cautious and not assume that what a white person or others say is best for them is indeed best.

### **Implications for Changes in Media Messages and Screening Services**

Study results have substantial implications for the needed development of new messages, channels, and programs to increase breast cancer screening participation rates in fiscally challenged African American women. The current linear model of screening, early detection, and treatment should give way to a model that links directly and early on with each woman's beliefs and perceptions about breast cancer, mammograms, and the woman's own model of factors that increase her personal risk for breast cancer. Outreach should initially be linked with each woman's view of breast cancer and screening mammograms, not with a predetermined list of risk factors or reasons why a woman needs a screening mammogram. Based on current study results, these messages and materials will not be effective in outreaching and engaging the women who participated in the current study. Namely, these are the women who, despite

outreach and existing messages, chose to not participate in a free mammogram screening program. Although existing messages and materials have documented success with other populations of women, they are a poor fit with the beliefs and attitudes of current study participants.

Based on study results, it would be misinformed to ask that community workers begin interacting with the woman by teaching them the importance of getting a screening mammogram. Instead, outreach workers should be trained on the use of interview methods that engage the woman in discussions about the woman's views about mammograms and screening, listening to her viewpoint as the first step. This form of education expands well beyond the typical, classical approach to information giving and instead moves toward personal engagement with the women's views. Motivational interviewing or personal coaching are two conceptual frameworks that could be added to the outreach worker's skills. Both frameworks provide specific, operational methods by which to engage the woman in sharing her viewpoints and beliefs. Both frameworks generate a dialogue, not a one-way message from the outreach worker to the woman. The role of the outreach worker in both is to attend to what the woman is saying and to use the woman's own views and words to help her make an informed decision about the appropriateness of obtaining a screening mammogram. Neither are manipulative strategies; both are health-enhancing strategies. At the end of the outreach dialogue, the woman will still have full decision making control, but her views will have been heard, clarified, and directly addressed by the outreach worker.

In the absence of obtaining the woman's views and beliefs about breast cancer and screening mammograms, there will likely be a negative backlash. Based on study

results, the woman may have no basis for believing the messages. Given evidence from the current study, such educational messages about the importance of obtaining a free screening mammogram may run counter to the beliefs the woman holds.

The title for the current DOD study was "Taking Care of Yourself" when it was discussed with the potential study participants, even though the title of the actual funded grant was a more formal scientific words. The study team chose the title, "Taking Care of Yourself" because we did not want to judge or inappropriately label the women's decision to not participate in a free screening mammogram. It turns out that such a title was a solid fit with what the women were doing; they were taking care of themselves, from their perspective, when they chose to not obtain a free mammogram. Such a title should be a phrase that represents whatever messages and materials are to be developed from the current study's results. Study participants chose to not participate in a free screening mammogram because they were indeed trying to take care of themselves.

Breast cancer became a socially constructed disease for the study participants. What it is, what it means to have it, and its outcomes were socially constructed, not merely biological facts. As such, new media images and messages need to include African American women, like themselves, who not only survived breast cancer, but thrived as whole, socially integrated and socially valued, women after the diagnosis and treatment of breast cancer. In the absence of such images, fiscally challenged African American women will have mainly negative or horrific images of having breast cancer. The women's dominant memories are of persons close to themselves who were diagnosed, often with late stage disease. These memories and images need to be complemented with new images of women like themselves who are doing well, including

the women's having primary intimate relationships with a man and primary relationships with their family, including grandchildren.

Radiation technicians, nurses, clinic receptionists, and medical providers need workshops or training programs that help them see how their verbal and non-verbal behavior create unnecessary social distance between them and the study participants. The interpersonal disconnection as well as perceived judgmental, diminishing environment in the clinic setting perpetuates a model of low trust, high caution, and low faith in the value of screening mammograms. Such disconnection also adds to the social construction of breast cancer screening as a negative experience for the woman. Training programs should begin with the assumption that breast cancer is a socially constructed illness, not a medical diagnosis. Such programs should emphasize the importance of sending desirable heuristic cues to the woman during the entire screening experience. African American women in the current study sample consistently defined themselves within their social context and the messages to self about self they received from others and the media. Provider settings and physical space should be re-evaluated as part of the workshop so that each provider setting can self-review their current practice and use of physical space as well as decide what and where modifications are needed. Photos of thriving breast cancer survivors who include women like themselves should be part of the media, photos decorating the screening sites. A story line from each of these thriving survivors could be part of the photo; it will not be enough to only have the photo.

Women benefit from stories of successful survivors; stories, not just photos, need to be part of the new program messages. The importance of stories again comes to mind: they had personal stories they shared in detail about persons affected by cancer; these stories were part of their view of the illness. Programs should honor those stories, not bury them. But stories with

negative outcomes need to be complemented [the word choice is purposeful] by stories of thriving survivors. Specific stories should include well adjusted spouses or intimate male sexual relationships as well as happy stories that include quality of life with grandchildren.

Changing educational and outreach messages and media are mandated by current study results. We can no longer assume that our current frame of reference in existing materials will suffice. Breast cancer and breast cancer screening should be cast within a larger cultural and ethnic context; results from the current DOD Idea Grant provide key content to generate new materials and messages.

### **Key Research Accomplishments**

1. A population data base of uninsured and fiscally challenged African American women can be successfully phone contacted by “cold calls,” but may require up to 10 phone contact attempts to successfully reach the women.
2. The greatest number of women “lost” to the study was due to 3 factors: non-functioning phone contact numbers; ineligibility determined by conversation with the women by the study intermediary, e.g., women stated they had obtained a screening mammogram from another source, not Breast & Cervical Health Program; or no one answered the phone when the intermediary contacted a working phone number. (We speculated that “caller ID” may have prevented some of the callees from answering.)
3. Potentially eligible study participants became ineligible for accrual because they claimed they had obtained a mammogram from another source; this claim may be truthful or due to social desirability bias. We were unable to determine the validity of the claim.
4. Most women, when successfully reached by an intermediary, were willing to be contacted by the study team.
5. Indigenous community workers can be successfully trained to conduct successfully elicitation interviews after participating in a specially designed training workshop developed for the current study.
6. Completed elicitation interviews yielded description and elaboration of the study participants’ beliefs, perceptions, and attitudes toward breast cancer and breast cancer screening. Results included new information that has not been previously documented in the published professional literature.
7. A partnership focused, capacity development paradigm for the conduct of this study was successfully implemented; members of the Community Advisory Committee were engaged in all operational, conceptual, and data analytic steps of this study, including functioning as reviewers for the credibility and interpretability of study results.
8. A Community Advisory Committee of stakeholders and community members was able to assume a major advisory and participatory role as supportive community partners in the conduct and direction of this population-based study.

9. On-going reports and regular meetings and data-based presentations with the Community Advisory Committee facilitated this research team's application for a grant to the Susan G. Komen Breast Cancer Foundation, Puget Sound Affiliate.
10. The attitudes and beliefs about breast cancer and screening of fiscally challenged African American women who participated in the completed study are inconsistent with the basic assumptions underlying the existing Breast & Cervical Health Program.
11. Personal models of understanding of causes of breast cancer run counter to data based results from data based studies of personal risk factors.
12. Breast cancer is a socially constructed illness that involves the entire woman, including her close interpersonal and family relationships; it is not a biomedical disease of the breast.
13. New media messages and training workshops for health care providers are needed that directly address the negative attitudes study participants held toward early detection and screening programs, including their belief that both the screening and diagnostic procedures are themselves the cause of problems or breast cancer.
14. Study results have major significance for the development of new cultural training materials and workshops for community outreach workers, medical care providers, and radiology technicians.
15. New methods of delivering the educational and outreach messages are needed that take into account the women's personal models of the causes and risk factors for breast cancer. Such methods need to engage the women in direct discussions of their personal models; "teaching" or merely telling them the medically correct biomedical information will likely be ineffective.

### **Reportable Outcomes**

#### **1. Funded Grant:**

Ellen Phillips-Angeles, PI & Frances M. Lewis, Co-PI. Increasing African American Women's Participation in a Breast Cancer Screening Program: Putting Research into Action. Susan G. Komen Foundation, Puget Sound Affiliate.

Based on results obtained through this Department of Defense Idea grant, we submitted and have recently been awarded a new program development grant from the Susan G. Komen Breast Cancer Foundation, Puget Sound Affiliate. Its purpose is to develop a new set of outreach and education materials for fiscally challenged African American women, their health care providers, and the community workers who identify potentially eligible women. These materials will include two professionally developed videotapes and two training workshops, one for health care providers and one for community outreach workers.

#### **2. Research Presentations:**

Ellen Phillips-Angeles, F.M. Lewis, Cobie Whitten, PhD & Rachel Bennett. "Taking Care of Yourself: Reasons African American Women Eligible for Free Services Decide Not to Have a Mammogram." Research accepted for oral presentation at the 9th Biennial Symposium on Minorities, the Medically Underserved & Cancer. March 24-28, 2004. Washington, D.C.

Lewis, FM & Phillips-Angeles, E. (2003). "Attitudes & Beliefs of Fiscally Challenged African American Women in the Breast & Cervical Health Program, Washington: Interim Results." Presentation made to the Executive Board, Susan G. Komen Breast Cancer Foundation, Seattle WA.

Ellen Phillips-Angeles & F.M. Lewis. (April 7, 2004). "Taking Care of Yourself Research Project." Symposium sponsored by Puget Sound Affiliate, Susan G. Komen Breast Cancer Foundation and partners, Eliminating African American Breast Cancer Disparities: Communities Moving from Statistics to Solutions (Puget Sound area)

Ellen Phillips-Angeles & F.M. Lewis. (July 12, 2004.) "Taking Care of Yourself Research Project," Washington Breast & Cervical Health Program, State Medical and Advisory Meeting (WA State-wide).

Ellen Phillips-Angeles & F.M. Lewis. (August 3, 2004). "Taking Care of Yourself Research Project", King County WBCHP Partners (King County).

### **3. Research Abstracts:**

Frances Marcus Lewis, Ellen Phillips-Angeles, Kathryn Bunt, B.A. & Lin Song. (2002). "Conducting Case Intensive Interviews with Fiscally Challenged African American Women Who Declined Free Screening Mammograms. Access, Accrual, & Refusal Rates." Poster presentation at the Department of Defense, Era of Hope Conference. Orlando, Florida.

### **4. Manuscripts:**

Frances Marcus Lewis, Ellen Phillips-Angeles, Dan Taber & Cobie Whitten. (2004). Beliefs about breast cancer and the logic of non-participation in screening programs: Policy implications for fiscally challenged African American women. (Under review; editorial decision pending).

Frances Marcus Lewis, Ellen Phillips-Angeles, & Lin Song. (2004). Challenges & realities in recruiting a population-based study sample through "cold calls." (Under review; editorial decision pending).

Dan Taber, Frances Marcus Lewis, & Ellen Phillips-Angeles. (2004). Worst fears and greatest concerns of African American Women with limited income about breast cancer: A pilot interview study. (Under review; editorial decision pending). [This manuscript is included in the Appendix.]

Frances Marcus Lewis, Dan Taber & Ellen Phillips-Angeles. (2004). Breast cancer as a social illness, not a biological disease: Results from a pilot study of fiscally challenged African American women. (Under review; editorial decision pending).

Ellen Phillips-Angeles, Frances Marcus Lewis & Dan Taber. (2004). The impact of knowing someone with breast cancer on relationships and breast cancer screening: A pilot interview study

of African American women with limited incomes. (Under review, editorial decision pending). [The main results text of this manuscript is included in the Appendix.]

Cobie Whitten, Frances Marcus Lewis, Ellen Phillips-Angeles, & Dan Taber. A mammogram as painful: Results from a pilot study of African American women. Manuscript under development.

## 5. Training Materials:

Frances Marcus Lewis. Interviewer Training Manual for Interviewer Training Workshop. See Appendix for complete Training Manual.

### Conclusions

The current study produced substantive, methodological, and paradigmatic findings.

#### Substantive Results:

Breast cancer is a socially constructed illness in the data obtained from fiscally challenged African American women in the current study sample; it is not a biological disease of the breast. As socially constructed, the meaning of breast cancer was linked to the women's self-identity, the feedback they received from both their intimate male partners and media, and the implications the illness had for their on-going and future social relationships with intimate partners, family and friends.

Women embedded breast cancer and screening services within the larger context of trust and mistrust with their medical providers. Their individual and prior cultural and ethnic history of being mistreated and experimented on (Tuskegee Institute studies) made many of them suspect and distrusting of physicians and other medical workers. They also thought that a mammogram was not to be trusted; it "missed" things.

Women did not think of breast cancer as limited disease of the breast. Instead, it involved their wholeness as a woman. Even talking about a mammogram as an isolated medical

procedure did not fit well with the women's view of themselves as whole women whose sense of self included all parts of their body. In the words of one woman,

*You know, if you care anything about yourself, take care of yourself. You know, um, I have my own personal issues as far as my weight goes, but everything else about me is perfectly healthy. You know, so I'm blessed in that area, but, you know, do you, do a check on all of you. Don't just weed that little part out. "Oh, I'll just check this part. Forget about the other part." You a whole package. So, check out your package.*

In addition to the main study results that were summarized earlier, women in the focus groups identified what they thought needed to be changed in the system of providing screening and related medical services to African American women. Their recommendations included these:

1. Use the screening mammogram appointment as a time for the mammogram technician to teach the woman;
2. Create a caring interaction with the woman being screened; do not treat her as a patient number, but as a person.
3. Create and sustain support groups for African American women in whom they can receive support and affirmations from other women like themselves.
4. Teach women to be their own best health advocates and to make sure they insist that they have the full attention and best medical treatment from their medical providers. Free service should not mean poor service.
5. Encourage a woman to have her own support person to help her take good care of herself, including reminding her of things. Although they talked about the importance of being strong, women in the focus group also argued for the value of having someone to support and affirm the woman.

#### Methodological Results:

An estimated 60% of personnel effort in this study dealt with recruitment: identifying, contacting, physically locating, accruing, and interviewing study participants for Phase 1 interviews and then re-locating them for the Phase 2 focus groups. Recruitment needed to be consistent, intensive but not intrusive, and longstanding. In the course of this study, the team used the skills of three different recruitment coordinators who were trained by Lewis and Song,

all of whom were exhausted during their individual tenure on the job. Lewis, Phillips-Angeles and Song each worked over time to strategize best ways to both update the contact numbers for potentially eligible women as well as to quality monitor the recruitment process and related spreadsheets. Dr. Song himself returned multiple times to clinic records in order to fastidiously track down the potentially eligible study participants' phone numbers and to cross validate them with those numbers appearing in the population data base of the Breast & Cervical Health Program. [Both Lewis and Phillips-Angeles were not permitted access to these confidential files, names or phone numbers until the woman granted permission to be contacted by the study team.]

Through over 36 months of this process, the investigative team came to deeply appreciate the distinction between a provider-based medical record data system and a population data-based system involving community members who had no consistent medical provider and who were sometimes homeless or transitioning between residences. The location of some of the interviews reflected the transitory nature of some of the personal residences of the participants, including libraries and public [but confidential] spaces.

Nothing could have prepared the research team for the onerous and exacting task of accessing study participants, nothing. As one of the senior team members stated after 2 years of struggling to enroll the initial pool of women, "Each woman is a needle in a huge haystack and we are trying to find her...and, there are thousands of haystacks!"

Although "cold calls" finally produced the study sample, it took over 2.5 years of constant, devoted work to accrue the final sample of study participants. It also required a tedious, detailed review of multiple population and historical and current clinic records to locate each woman. See poster in appendix by *Lewis, Phillips-Angeles, Bunt, & Song. (2002)*. "*Conducting*

*Case Intensive Interviews with Fiscally Challenged African American Women Who Declined Free Screening Mammograms. Access, Accrual, & Refusal Rates."*

The struggle to physically locate and accrue study samples in both phases of the study occurred because the phone numbers in the state-wide initial data base were often outdated and, in some cases, were linked to places like a homeless shelter, not a personal residence. (*Lewis, Phillips-Angeles, & Song. 2004. "Challenges & realities in recruiting a population-based study sample through "cold calls." Under review; editorial decision pending*). It took an additional 7 months after Phase 1 interviews to successfully locate and then re-contact women who participated in the Phase 1 interviews and agreed to be re-contacted for the Phase 2 focus group interviews.

Future research with a population-based study of women should first verify the accuracy of their phone numbers. Such verification would prevent launching a study whose data base was substantially outdated. Future programs and services for women in a community sample, like those in this completed Idea Grant, should document a minimum of THREE phone numbers from which to contact the woman. By recording 3 phone contact numbers, future studies will not be vulnerable to the record errors that the current study team experienced.

Paradigmatic Results:

This completed Idea Grant was based on a community partnership, capacity development model that involved community members and stakeholders. It required that community members and stakeholders were immediately and consistently engaged over time at every juncture of the research process. Phillips-Angeles assumed major leadership to identify, invite, and sustain the engagement of all the relevant community members.

Although Lewis, Phillips-Angeles, and Song were the senior investigative team who wrote the research grant application, as soon as it was funded the team convened over the entire duration of the grant a Community Advisory Committee. This committee initially met every 1-2 months for the first year of the study and then moved to quarterly meetings during subsequent years.

Under the leadership of Phillips-Angeles, membership in this committee was expanded to include both medical providers (e.g., Drs. Dawson and Hayes, MDs) as well as state-level and county-level members of the public health and Breast & Cervical Health Care Community (e.g., Cobie Whitten, Karen Fennell). In addition, health care agencies and women's community service agencies were well-represented (e.g., YWCA, Tacoma-Pierce County; Cancer Information Service of Western Region), along with foundation leadership (Cherie Minear, Susan G. Komen Foundation).

Every staff position that was funded by the Idea Grant was also offered to community members first. Only when that position could not be filled by a community member was it opened for others. The complete list of personnel funded on this grant is listed in Figure 6.

Engaging the community partners and stakeholders required a focused and systematic commitment by the study team. Each meeting had to be planned in advance, along with materials to present and be discussed. Our goal was to assist the community members be full partners in the research process as well as "own" and be able to use and interpret the study findings as they emerged. We wanted to avoid a roll out of study results only at the end of the study; deep dialogue was our focus, not superficial presentation.

Figure 6: Salaried Personnel on Grant Budget

- Barnett, Carolyn J. (trained interviewer; transcriptionist)
- Bennett, Rachel J. (interviewer & assistant research manager)
- Bunt, Kathryn M. (assistant research manager)
- Cruse-Adler, Donna (data coder for early interviews))
- Davis, Jennifer B. (assistant research manager)
- Davis-Kirsch, Sallie E. (data coder for early interviews)
- Hales, Lisa E. (transcriptionist)
- Knox, Courtney A. (transcriptionist)
- Lewis, Frances M. (Principal investigator)
- Nguyen, Linda T. (transcriptionist)
- Perrin, Michele R. (interviewer)
- Phillips-Angeles, Ellen (Co-PI)
- Richardson, Bridgette (interviewer)
- Song, Lin (Co-PI; epidemiologist and data manager)
- Sulayman, Aminah (transcriptionist)
- Taber, Daniel R. (data coder)
- Williams, Henrietta (interviewer)
- Wu, Salene (transcriptionist)

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## **Appendices**

## **Appendix: Example Paper under Review; editorial decision pending**

Worst Fears and Greatest Concerns of African American Women with Limited Income about Breast Cancer: A Pilot Interview Study

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## **ABSTRACT**

Breast cancer screening programs are based on a rational model that assumes that the detection of early disease through screening mammography can save a woman's life. Evidence from the current study is that fears and concerns about breast cancer are experienced by women who chose to not be screened when offered free services in a county-wide screening program. The authors speculate that these fears and concerns likely influenced the woman's decision to not participate in what otherwise would be a neutral screening mammogram. Results to be reported were derived from confidential, face-to-face interviews with 43 African American women with limited income who declined participation in a free screening mammogram program. Seven domains of concerns and fears were identified from inductively coded interview data; these fears and concerns need to be addressed directly in future breast cancer screening outreach messages and materials. To not attend to these fears is to have an elephant in the living room that no one is talking about.

Keywords: *breast cancer; mammography; African-American women; fears; cancer screening*

## INTRODUCTION

In 2004, an estimated 275,380 women will be newly diagnosed with breast cancer in the United States. This figure represents an increase from 2003, when an estimated 268,300 women were newly diagnosed with breast cancer. Among those who were diagnosed in 2003, more than 20,000 African American women were newly diagnosed, exclusive of in situ disease. From 1999 to 2001 in the state of Washington, there was an age-adjusted rate of 137.8 new cases per 100,000 per year among African Americans.

Not only are rates of disease a public health issue, the *stage* at which the disease is diagnosed is of concern. When diagnosed early, breast cancer is a potentially curable disease. When the disease is confined to the breast, the 5-year survival rate was 97.0% from 1992-1999; when diagnosed at a distant stage, the 5-year survival rate for the same time period was only 23.3%.

Completed studies of populations have shown that African American women are more likely to be diagnosed with advanced disease at initial time of diagnosis than are Caucasian women. In a recent case-control study of African American women, being African American significantly predicted the diagnosis of advanced stage (odds ratio: 3.0; 95% confidence interval: 1.9-4.7) as did having a low income (OR: 3.7; CI 95%: 2.1-6.5) and being uninsured (OR: 2.5; 95% CI: 1.6-4.0).<sup>7</sup> Between 1999 and 2001, 30% of the new cases among African American women in the state of Washington were diagnosed as regional or distant stage, compared to 27% of the new cases among Whites.<sup>4</sup> African American women are also more likely to be diagnosed with large tumors compared to white women. From 1996 to 2000, 46.4% of breast cancer cases among African American women nation-wide were diagnosed with tumors larger than two centimeters, compared to 32.3% of breast cancer cases among white women nation-wide.<sup>5</sup>

Breast cancer screening programs offer the most promise for early detection of the disease. Despite the link between early detection and cure, however, women do not always participate in breast cancer screening programs, even when the programs are available, accessible, and are offered free of charge to participants. Historically, African American women have been at particular risk for lower screening participation rates compared to white women.<sup>5</sup> Recent studies have found that African American participation rates are still less than optimal, especially when measuring regular use of screening rather than simply one-time use. Low participation rates for these women mean that they are more likely to present, at time of diagnosis, with advanced disease. Taken together, these statistics mean that participation in breast cancer screening programs is essential to the early diagnosis, disease down-staging, and treatment of breast cancer for all women, including African American women.

Although there have been studies of factors affecting women's utilization rates in breast cancer screening, we have very few studies, especially population-based studies, that involve African American women.<sup>7</sup> We have even fewer studies involving African American women who are uninsured or who have limited incomes. Furthermore, there is no known study of this population who were outreached and offered a free screening mammogram as part of the Washington Breast and Cervical Health Program (WBCHP) but decided to not have a screening mammogram.

There is a beginning literature that suggests that cultural beliefs and values may affect African American women's decisions to participate in a breast cancer screening program. Fatalism, religious beliefs, confidence in alternative treatments, and women's reluctance to discuss cancer with their husbands are examples of cultural values that have been shown to influence stage at diagnosis among African American women. One study suggested that

attitudinal barriers may be a greater obstacle to screening than access issues, and that fears of cancer are among the greatest attitudinal barriers. A recent study established fear as the primary reason that a sample of African American women did not engage in breast cancer screening.

The goal of this pilot study was to document what African American women with limited income **feared most** and considered the **worst thing** for a woman to be diagnosed with breast cancer. By understanding African American women's fears and perceptions, health educators and program planners will be able to develop more informed, sensitive programs, messages and materials that can enhance participation rates in breast cancer screening programs. Ultimately, such participation is our best known method for detecting breast cancer at an early stage, thereby minimizing the mortality and morbidity risk for African American women.

## METHODS

Face-to-face interviews were conducted with African American women with limited income who were invited to participate in a free screening mammogram through the WBCHP in the Pacific Northwest. Interviews were conducted by specially trained interviewers as part of a larger community partnership study. After signing informed consent, women were interviewed in a confidential, quiet setting of their choosing, most often their home. Data to be reported in the current study derive from the women's answers to two questions:

1. What are your greatest fears, if any, that you have about breast cancer?
2. What is the worst thing you can imagine if you were to be diagnosed with breast cancer?

Interviews were audiotape recorded and ranged from about 20 to 50 minutes in length.

All tape-recordings were typed exactly as recorded; no editing was done to alter the woman's statements. The transcriptions were verified for accuracy by comparing the transcription with the tape-recorded interview by a trained research assistant.

A multi-phased process was used to analyze the transcribed interview data based on content analytic methods. See Table I for a summary of the steps that were used in the data analysis. These steps are briefly described next.

The transcribed data were initially unitized. The unit of analysis that was to be coded was the complete idea, not the complete sentence. A complete idea was defined as a verbal expression that included both an explicit or implicit verb and noun. As a result, compound sentences were analyzed into their component parts and coded as multiple units.

Open coding occurred after unitizing the data; this involved analyzing, comparing, and categorizing data<sup>21</sup>. Each unit of analysis was reviewed and organized into categories of units based on some common element. This resulted in non-overlapping categories. Precursors or antecedents as well as consequents were coded into separate categories and were not part of the same categories. For example, the causes [antecedents] of a woman's greatest fear about breast cancer were coded into separate categories than were the qualities or aspects of her fear. This was important so that we could examine the relationship between fears and their causes and their consequences.

Initially, interviews for each question were coded separately. After both questions were coded [greatest fear and worst thing], the analyzed responses were grouped together into an integrated set of categories. The categories were based on the manifest, not the latent, content and meaning of the words<sup>18</sup>.

Categories were labeled with emic, not etic, labels<sup>24</sup>. Emic labels are labels in the words of the participants, not the coder. Emic categories are synonymous with "in vivo" codes or codes based on the words of the study participants<sup>23</sup>. Constant comparative analysis occurred concurrent to the identification of the categories and involved three comparisons. First, each unit

of data was compared with each category in order to maximize the fit of the unit with the category. Units of analysis were also compared with each other within each category in order to maximize the consistency of the grouped units. Finally, all categories and units of analysis were compared with the other categories and units in order to maximize their unique and non-overlapping quality.

During the entire process, definitions of the categories were developed and refined in order to better reflect the distinctions being made both within and across categories. Any disagreement about any aspect of the coding was resolved through discussion. Such discussions resulted in either a refinement in the definition of the category, a reassignment of the unit of data, the identification of a new category, or the identification of dimensions within a category.

To add to the clarity and parsimony of the analysis, categories were continually reviewed and refined in order to identify an increasingly parsimonious set of categories and definitions. Once the categories were sufficiently refined, conceptual domains were generated that further organized the categories. See Table II. Multiple processes were conducted to assure the trustworthiness of study results: peer debriefing, member checks, and the establishment of an audit trail.

## **RESULTS**

### **Study Sample**

A total of 43 African American women participated in this pilot study. All women were identified from a population database of women who were outreach as part of WBCHP of Washington state but who decided to not obtain a free screening mammogram. As part of the data collection, women were categorized into 4 groups on the basis of their decision not to obtain a mammogram: Category 1 women were outreach, but did not enroll in WBCHP; Category 2

women refused a mammogram at enrollment; Category 3 women were enrolled and had an initial mammogram, but refused a mammogram in subsequent cycles; Category 4 women were enrolled and had an initial mammogram, but did not return for re-screening within two years or more (26.3% of the women were Category 1, 10.5% were Category 2, 23.7% were Category 3, and 39.5% were Category 4).

Women for whom we have data ranged in age from 40 to 76 years with a mean of 52.375 years ( $SD = 7.71$ ) and a median of 51.50 years. Data were not available on 3 women.

A substantial majority (97.0%) of the women had household incomes below the poverty level, and 93.8% did not have health insurance and 96.9% did not have Medicaid. Most (97.4%) of the women lived in neighborhoods in which at least 5% of residents were living below the poverty level; 20.5% lived in neighborhoods where at least 20% of residents were below the poverty level. Of the 33 women who reported their birth country, all but 2 were born in the United States (1 was born in Canada and 1 was born in West Africa). The majority of women (77.5%) had at least a high school education; 47.5% had some college education. Four women had graduated from college. The women had an average of 2.83 children born to them ( $SD=2.32$ ), with an average of 0.85 children still living in their house ( $SD=1.19$ ).

### **Domains & Categories**

Seven conceptual domains and twenty-seven categories were identified from the analyzed data. See Table III. These seven domains were: 1). Cutting into my time; 2). Worrying how this will affect my family; 3). Suffering through treatment and cancer; 4). Cancer eating my body; 5). Just knowing that I have breast cancer; 6). Dealing with it; and 7). Crossing that bridge when I come to it. The domains are described next along with their related categories.

### **DOMAIN 1: Cutting into my time**

The women's greatest fear was that their life would be cut short by cancer. Dying in and of itself, however, was only one dimension of the fear. Being in a situation where one is forced to accept death, with no options for cure, frightened many women more than simply the act of dying. Stated differently, the true fear was feeling no control over when you live or die.

**Dying:** Death was candidly presented by some women as being their greatest fear, if not their only fear. Though the topic was the *worst* thing women could imagine, some women spoke as if death were the only possible outcome. Their concepts of cancer included statements such as, "To me cancer is a death sentence" and "I just know [cancer] will take your life if you have it." One woman explicitly expressed her skepticism towards cancer treatment being able to prevent death: "I do think that they don't have a cure for cancer, no type of cancer ... [the Lord] may just prolong your life to give you a little longer to live you know, but it eventually comes back and gets you and kills you. So when you get cancer you're through."

**Knowing it was too late to fix:** Several women spoke of a worst-case scenario in which the cancer diagnosis came at a late stage when the cancer could not be treated. This fear of late-stage cancer had three facets to it: being forced to confront imminent death ("your mortality hit you right in your face again"), the powerlessness of not being able to treat the cancer ("that it was in the probably the last stages of it where there was no prevention or anything to stop the breast cancer"), and the knowledge that treatment could have taken place had the cancer been detected earlier ("it could have been maybe stopped ahead of time if it was something that was small, if it had been detected earlier").

**Feeling that my life is incomplete:** Some women who spoke of mortality fears focused primarily on the feeling that their life was incomplete. They feared a premature death, at a time when they had not accomplished everything that they wanted to in life. As one woman phrased

it, her greatest fear was “to leave this space, this planet, without having really done what I wanted to do.”

**Not knowing if I will live or die:** The uncertainty of outcome was the greatest fear to some women. Particularly in dealing with a disease for which there is no absolute cure, these women feared going through the entire cancer experience never knowing if they would survive: “You just don’t know if you’re gonna (sic) live or you’re gonna (sic) die.” This uncertainty sometimes carried an underlying skepticism towards any treatment: “I know there’s no cure for cancer, really, even if you catch it in time,” said one woman. Another commented, “sometime if dey say dey, dey got it all, it it can come back, you know.”

#### ***DOMAIN 2: Worrying how this will affect my family***

Rather than focusing on their own lives, some women specifically discussed how the cancer experience would impact their family lives. The focus of each woman’s greatest fear about her family life varied. Some women expressed a sense of personal loss, fearing that their families would be taken away from them. Others focused more on how the family itself would be impacted—that is, how their spouses, children, and grandchildren would cope with the disease. In almost no case, however, did the woman express a fear that her death and subsequent absence would hurt the family. If anything, she was afraid of being a burden on the family while alive, rather than burdening her family through her passing.

**Not seeing my kids and grandkids grow up:** Wishing to see their children and grandchildren grow up was the greatest concern to several women. Women who expressed this fear almost always spoke of it as a personal loss of their own—“I wouldn’t get to see my kids and grandchildren,” “it will take me from my family”—rather than communicating it as though the woman’s absence would be a loss to the children/grandchildren.

**Draining my family:** Many women emphasized the cancer taking an emotional toll on family, particularly their children. Women did not want to be a physical or emotional burden on the family while alive. One woman even feared that the cancer experience would be more painful for her family than for herself: “It would be so painful for them. Their concerns would be so hard for them, not for me.” Another woman echoed the feeling that family concerns would be worse than the cancer itself, by stating “watching my children worry about me would probably be harder than actually having the cancer.”

Some women seemed particularly concerned about cancer changing their image within the family, from caretaker to the one being cared for (“I would have to have my family to take care of me like an infant because I couldn’t take care of myself.”) Three women talked about not wanting their family to see them suffer or pity them: “I don’t want to let my kids see the cancer,” “When I die and I’m buried, don’t be crying over me,” and “I don’t want my kids, grandkids to be sad that I’m dying.”

**Losing my husband:** Some women did not know how their husbands would react to breast cancer, and feared that the husbands would reject them, “pulling away, being repulsed” if they were diagnosed. Other women did not even question what would be the reaction, but simply assumed that men would reject them. Those who feared rejection usually spoke in the context of having a mastectomy—that is, they seemed to worry more about being rejected for losing a breast than for having a disease that might kill them. They believed that losing a breast would affect their feminine image. Women expected to be ignored, if not “exploited, rejected, laughed at, taunted” if they were to lose a breast. Some women also expressed self-shame at the thought of losing a breast, aside from men’s reactions: “[I would] not want a man to even see me period.”

**Fearing that my daughters will get it:** One woman's response to the idea of herself getting breast cancer was to immediately fear that her daughters would get it.

***DOMAIN 3: Suffering through treatment and cancer***

The pain of cancer and subsequent treatment while one is alive was, in some women's eyes, a greater fear than death itself. The focus was on the physical impact that the entire cancer experience would have on a woman's life assuming that she survived. The worst thing was not to have the woman's life taken away, but rather to live a life filled with pain and suffering.

**Fearing treatment:** Many women feared chemotherapy and surgery, and the physical impacts of these treatments, more than cancer. Treatment was sometimes seen as torturing rather than life-saving: "It seems like it gets into your body and does something strange to your body." One woman conveyed her mixed feelings toward treatment by saying, "That, to me, that's suffering ... either the treatment's gonna kill you or it's gonna cure you." Women commonly feared nausea, losing one's hair, and overall "watching my body just be deteriorated."

Other women were not even ambivalent towards chemotherapy and surgery, instead seeing these treatments as a threat to their health. Surgery, in particular, was viewed by some as a way for the cancer to spread: "they cut on you and the next thing you know it's spread to some other part of your body."

**Being in excruciating pain:** Women spoke of fearing pain, but it was not always clear whether they were referring to physical, mental, or some other type of pain. Their descriptions of pain were vague—"I'm not big on pain," "Living and being in pain," and "I would suffer." This may have reflected their vague concepts of breast cancer, as some women who specifically referred to physical pain seemed to not have clear ideas of what cancer would feel like. Their

descriptions included “Your cells are just going crazy inside your body and I can’t imagine what the pain feels like,” and “I hear cancer is painful.”

**Suffering for a long time:** Many women viewed cancer as a chronic condition which would cause long-term suffering. They feared a disease which would “wear you out” over a long period of time. They anticipated not only the physical, but also mental tolls that the prolonged suffering would take: “It would be on my mind every day. Every single day.” One woman specifically stated that immediate death would be preferred over prolonged suffering: “I wouldn’t be so much worried about it if I … if it was at a point in which I was to die.”

**Not being able to do things that I used to do:** To some women, the worst thing they could imagine was to not have the physical capacity to support themselves. Freedom and control were common themes as women expressed fears of “not being able to have control of your, of your everyday situation.” Women also feared relying on others for assistance, being “dependent on people to help you when you know you need it.” One woman, referring to people she knew who had breast cancer, summed it up as “even though they have taken tests and taken tons of medications and spent tons of money, their life was not the same ever again.”

#### ***DOMAIN 4: Cancer eating my body***

Beyond fearing the physical impacts of the cancer experience on their bodies, women also feared feeling a loss of ownership toward their bodies. Many women viewed the cancer not as something that could take their life or ruin their quality of life, but as a threat to take away their bodies both literally and symbolically. Women clearly felt an emotional connection with their breasts, as well as an awareness of how their body feels (i.e. whether they are healthy) at any given moment. Consequently, feeling a sense of invasion and loss of control over one’s body seemed to be the equivalent of losing one’s life or giving up control over one’s life.

**Losing my breast:** Many women discussed how having a breast removed would be more of a psychological loss than a physical loss. One woman even claimed, “I think having a mastectomy and trying to deal with that would be worse than dying.” Women found many different words to convey the emotional significance of their breasts, all communicating that the breast was more than just another body part: “[your breast] is a part of you that’s … you know, that is you.”

Women expressed a range of emotions toward the thought of losing a breast, including fear (“Don’t do this to me, don’t take my breast, that scares me”); sorrow (“People say there’s a real sense of loss”); insecurity (“I could see where someone who had lost their breast wouldn’t feel normal anymore, you know, like a woman”); and guilt (“I’d always feel guilty and shy even if I did have an augmentation”). Some added that they would need support if they had a mastectomy (“I would probably have to seek some type of counseling to help me through that”).

**Feeling like your body isn’t yours anymore:** One woman described feeling that her body would not be hers if she had cancer: “It’s an invasion of your body and it seems to me that once it gets in there, unless you find it really early, then your body’s not yours anymore.”

**Not knowing that I have it:** Two women, in discussing their fears, talked about their awareness that they could already have cancer and not realize it. Both women seemed concerned with the thought of not knowing what was happening within their bodies. One of them directly said that her worst fear was not knowing that she had cancer. The other did not sense that she had cancer, but subsequently acknowledged that she might not be aware of it even if she did have cancer—“I don’t feel like I have it, but how do you feel if you know you have it.”

**Cancer spreading:** To some women, fears about breast cancer were not limited to the breast. They were aware of the cancer’s ability to spread to other body parts, and they feared

“cancer eating my body.” Another woman added, “If you have cancer and it’s spreading; where are you going to go?”

#### ***DOMAIN 5: Just knowing that I have breast cancer***

Several women stated that simply knowing that they had breast cancer would be worse than any of the effects of the disease. Women conveyed a lack of faith in their ability to cope with breast cancer. They also detailed the emotional turmoil that they would feel immediately upon being told the diagnosis. The focus was not on the long-term emotional struggles, nor the health threats presented by cancer. Instead, the worst thing imaginable was an immediate inability to deal with diagnosis. There was often a sense of helplessness as women felt as though they would have nowhere to go if they were diagnosed: “What am I gonna (sic) do? It’s like, where do I go from there?”

**Finding out that I have cancer:** Some women solely spoke of their fear of learning that they have cancer, and did not discuss the impact that cancer would have on their lives. This fear was often phrased specifically as a fear of the diagnosis or the act of being told that one has cancer: “I just don’t want to ever be diagnosed with cancer,” “first, they got to tell me I have it,” and “I wouldn’t want to hear the words, ‘Okay, you’ve got cancer.’”

**Going off the deep end:** Some women clearly did not have confidence in themselves to cope with the disease upon diagnosis. While some only expected a temporary panic—“freak out, go off the deep end for a minute”—others expressed more doubts about their long-term ability to deal with breast cancer. For example, one woman shared, “I’d probably go on a, the worst scenario, self-destruction mode.” One woman went as far as to say, “The psychological ramifications from that [having breast cancer] is probably worse than the disease itself.” Another

woman noted that she would need intervention just to deal with such ramifications: "you need some type of intervention or medication to keep your mind at a balanced keel."

**Wondering "Why me?"**: Several women said that, if diagnosed, they would immediately wonder why it happened to them. Some of these women had an underlying philosophy that a person develops breast cancer only if she "deserves" it. For example, one woman said that her response to diagnosis would be "What did I do to deserve this? What did I do wrong in my life?"

To one woman, the "Why me?" question focused on her religious beliefs and self-evaluation, as she reflected, "maybe [the Lord] is trying to teach me something ... maybe my life has been too easy ... and I need to be put on the suffering side of things to appreciate life a little more." To other women, however, the question was based on the woman's assumption that she should not have developed breast cancer. Either the woman felt that she had done everything not to get it, such as by having checkups with her doctor, or she believed that she was not susceptible to breast cancer because there was no history of it in her family. Some women even said that they would blame the doctor if they were diagnosed. One woman, pretending to address her doctor in the interview, said, "Why didn't you catch it early, because I kept my appointments, and why didn't you see it then?"

**Not knowing what to do:** What do to immediately after diagnosis was a cause of concern for some women. They expressed helplessness in not knowing what to do in response to the cancer and not knowing what resources would be available to them. This included feeling like they had no emotional support ("Who can I contact with for support other than my husband?") or financial support ("I couldn't pay for treatments. I have no health insurance.")

While each of the domains presented to this point dealt directly with the women's fears, some women preferred not to talk about their fears even when asked. Instead, they focused on their ideas about how to cope with the threat of breast cancer, both before and after diagnosis. Women had different notions of how best to cope with the threat; the different approaches are summarized in the last two domains, to be described next.

#### ***DOMAIN 6: Dealing with it***

Rather than discussing their greatest fears, some women chose to discuss how they would confront the disease if they were to be diagnosed. Women concentrated on ways that they could overcome the cancer, or at least make the most of the remaining life that they had. This approach, however, often seemed to rest on the assumption that a person should just accept death or whatever the outcome may be, as if to say that there was nothing one could do to influence the outcome of the cancer.

**Not giving up:** Many women preferred not to pity themselves, insisting that they would not let the disease bother them. Different women had different notions of what it meant to not give up. Some spoke in passive terms—"deal with it"; "accept what's gone on"; "try to not let things like that bother me"—about coping with the disease. In contrast, others spoke about actively "fighting" the cancer. "You may catch me off guard, but we're still going to fight," stated one woman. "I would not give up. I would not give up," another woman said.

Women tended to speak in vague language—"I would just do what I had to do and go on," "I hope I don't get it but if I do I'm gonna deal with it." They did not provide specific examples of what they would do to either "deal with" or "fight" the cancer. They also only spoke about dealing with the disease as a whole, and generally did not discuss dealing with specific effects of cancer and treatment, e.g., the side effects of chemotherapy. Only one woman

specifically stated that she was willing to have her breast removed in order to treat the cancer: "If [removing my breast] meant that it would save my life and I could go on and be functional ... I'd be okay with that."

**Getting closer to God:** Religion was often discussed as a means of coping with breast cancer. Many women already possessed a strong belief in God, and either drew strength from their beliefs or had a strong conviction that God could cure cancer. "I believe, if I got it, I believe the Lord'll (sic) heal it," one woman explained. Some went as far as to say that *only* God could treat the cancer: "You're looking to man [to cure breast cancer] and man is limited." Most of these women who discussed religion only spoke of their individual faith and how their personal relationship with God could help them fight cancer. Only one woman discussed how the support of her church would help her.

**Making the best of the time I had:** Some women chose to focus their discussion on what they would do with their remaining time, were they to be diagnosed, as if they accepted that death was inevitable. Their primary concern was being able to "go on and take it and live life to the fullest." To one woman, living a full life included encouraging other women to get screened so as to avoid having the same experience. Others specifically discussed leaving their children with positive memories: "I want [my kids and grandkids] to have a good time while I'm alive," "leaving a positive legacy for my children and my immediate brothers and sisters."

**Wishing I knew survivors:** One woman believed that it would make a difference to her if she knew people who had survived breast cancer. Knowing survivors would prove to her that "there is life beyond, you know, not everybody has to die."

***DOMAIN 7: Crossing that bridge when I come to it***

Some women preferred to only deal with the disease if it arose. Coping with breast cancer was something they chose, either consciously or subconsciously, not to think about. These women have various reasons for not expressing any fears of breast cancer, but the prevailing belief among them was that fearing cancer or death had no benefit.

**Not knowing how I would react until it happens:** Some women said that they could not anticipate how they would react to having breast cancer unless it actually happened. Hence, they did not have any particular fears toward the disease. In some cases, the woman seemed to imply that there was nothing she could do to stop the cancer, but could only react after it developed. Though she was aware that there are different stages of cancer, she did not seem to believe that her behavior could affect the stage, “I would just have to see what my chances are ... how far advanced that is, and just, live accordingly.”

**Trying not to think about it:** There was a common belief that thinking about cancer was a waste of time and could even potentially harm a person. One woman feared that dwelling on breast cancer could actually cause the cancer to develop: “I do believe that you can manifest that [the breast cancer], by thinking about it a lot.”

The degree to which women actively *avoided* thinking about it varied. Some said that breast cancer simply never entered their mind, possibly because there was no presence of it in their lives, “I’m not dealing with it personally in my life, so therefore, I don’t think about it”. Conversely, one woman admitted that, “it’s kind of like being in the dark...it’s almost like you feel more secure.”

**Not fearing cancer or death:** Several women explicitly said that they did not fear getting cancer or dying. They identified several reasons for their lack of fear: belief that she was not vulnerable to cancer (“Nobody in my family ever had it ... I’ll never get it”); belief that one

cannot do anything to prevent it ("you're going to get it anyway"); religious beliefs ("because I'm a Christian, I don't fear death," "death is simply a sleep until the Resurrection"); confidence in treatment ("if they get it early, I know they're going to go in there and do what they have to do"); and feeling desensitized by previous experience ("I really don't fear it to be honest 'cause (sic) I've dealt with it so much").

## **DISCUSSION**

Fears and concerns about breast cancer were elaborated in the interview data of African American women with limited income who chose to not obtain a free screening mammogram through a county-wide screening program.

Results are limited to data obtained from 43 women who were identified through a population data base. Although different results might be expected from other women, interview data reached saturation in the categories.

Interview data were limited to single occasion, face-to-face interviews conducted by specially trained interviewers who were previously unknown to study participants. Data derived from these interviews may suffer from bias, particularly self-enhancement or recall bias.

Although each interviewer completed a 6-hour training program by the second author, the extent to which each interviewer invited the women's elaboration of text substantially varied. Future studies should encourage a fuller elaboration of the women's responses to each interview question.

## **IMPLICATIONS**

The women's fears and concerns need to be addressed directly in future breast cancer screening outreach messages and materials. To not attend to these fears is to ignore part of their perceived reality about breast cancer. Fears and concerns could be addressed through messages

and materials that are organized around Protection Motivation Theory or Social Cognitive Theory. In both these theories the health educator could directly identify the fears and concerns that were commonly held by women, along with ways to manage them. Given current study results, it seems naïve, if not ineffective, for health education and outreach messages to be limited to messages about only the positive aspects of screening programs for breast cancer. Such positive messages need to be complemented with managing and directly addressing the women's fears and concerns. Recall that the women interviewed in this study were outreached by community workers but chose to not be screened. Existing materials and outreach messages may be effective in bringing in women other than those included in the current study, but such messages are not successful for women interviewed in the current study. This study demonstrates beliefs about breast cancer screening that are key for a sub-set of the priority population for the breast and cervical health programs in the United States. It is essential to develop new and appropriate education messages that address these concerns so that more women can take advantage of breast health screening.

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## **TABLES**

### **Table I: Summary and Sequence of Data Analysis Steps**

**Step 1:** Transcription of interviews

**Step 2:** Verification of transcribed data against audiotape-recording

**Step 3:** Establishing units of analysis of transcribed data; peer debriefing of units

**Step 4:** Organization of units of analysis into initial categories; peer debriefing

**Step 6:** Generation of definitions of categories; constant comparative analysis; peer debriefing

**Step 5:** Refinement of initial categories and their definitions; constant comparative analyses; peer debriefing

**Step 6:** Organization of categories into larger conceptual domains; constant comparative analysis; peer debriefing

**Table II: Characteristics of Participants**

<b>Variable</b>	<b>Mean</b>	<b>SD</b>	<b>Min.</b>	<b>Max</b>
Age (years)	52.375	7.71	40	76
# children born	2.83	2.32	0	12
# children living in house	0.85	1.19	0	5

**Education**

None		1	2.5
Grade school		2	5.0
Some high school		6	15.0
High school diploma or equivalent		4	10.0
Technical school or some community college		7	17.5
Community college graduate		1	2.5
Some college		15	37.5
College graduate		4	10.0
Missing data		3	

**Ever had mammogram?**

Yes		20	60.6
No		11	33.3
Unknown		2	6.1
Missing data		10	

**Ever had pap smear?**

Yes		27	84.4
No		2	6.3

Unknown	3	9.4
Missing data	11	
<b>Relative with cancer?*</b>		
Yes	4	28.6
No	10	71.4
Missing data	29	

\* - participants were asked if a sister, mother, or daughter had been diagnosed with breast cancer

**(Table II cont.)**

<i>Variable</i>	<i>N</i>	<i>%</i>
<b>Medicaid?</b>		
Yes	1	3.1
No	31	96.9
Missing data	11	
<b>Insurance?</b>		
Yes	2	6.3
No	30	93.8
Missing data	11	
<b>Income below poverty level?</b>		
Yes	32	97.0

No	1	3.0
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Missing data	10	
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#### **Neighborhood poverty level**

<5% living below poverty level	1	2.6
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5-20% below poverty level	30	76.9
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>20% below poverty level	8	20.5
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Missing data	4	
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#### **Currently have breast symptoms?**

Yes	6	15.0
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No	34	85.0
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Missing data	3	
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#### **WBCHP Enrollment**

Outreached, did not enroll	10	26.3
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Refused mammogram at enrollment	4	10.5
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Refused mammogram in subsequent cycles	9	23.7
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Did not return for rescreening	15	39.5
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Missing data	5	
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#### **Birth country**

United States	31	93.9
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Canada	1	3.0
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West Africa	1	3.0
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Missing data	10	
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**(Table II cont.)**

<b>Variable</b>	<b>N</b>	<b>%</b>
<b>Interviewer</b>		
Bridgette Richardson	14	32.6
Michelle Perrin	6	14.0
Rachel Bennett	10	23.3
Rietta Williams	13	30.2

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**Appendix:**

The Impact of Knowing Someone with Breast Cancer on Relationships and Breast Cancer

Screening: A Pilot Interview Study of African American Women with Limited Incomes

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## RESULTS

### Domains & Categories

Thirty of the forty-three women interviewed knew someone who had breast cancer. Most were close relatives or friends, so a context was described for each woman. This is what makes the experience so challenging, memorable and often difficult. It is the impact of breast cancer on that valued relationship. "I've had two friends that had breast cancer. One of them went in for a check-up and found out she had breast cancer. The doctor had given her, I think, so many months to live, and she lived eight years. We did so many things together. It really didn't take a toll on her body for five years. She changed her eating habits because she explained to the doctors that she didn't want to go on chemo. She wanted to do a naturalistic approach, so they gave her the proper foods to eat and she did that. She went into remission for about three years and then it started up again after that. So, she lived eight years and then she passed away." Many interviewees mentioned the outcomes: six women lived, twelve women died, eleven women "took it real well" and three women were survivors.

Nine conceptual domains and fifty-five categories were identified from the analyzed data. See Table III. These domains were 1) Taking a toll on you emotionally; 2) Learning from my friend; 3) Finding it early; 4) Increasing your risk; 5) Protecting yourself from breast cancer; 6) Looking to God; 7) Getting cancer treatment; 8) Helping my friend; 9) Getting poor medical care. The domains are described next along with their related categories.

#### *DOMAIN 1: Taking a toll on you emotionally*

The emotional toll of knowing someone with breast cancer had the strongest impact. Feelings were deep, strong and long lasting. The women expressed feelings at every stage from seeing her friend diagnosed with breast cancer through various treatment, recovery, and survivorship and in some cases death. They experienced emotional pain and suffering from knowing someone with breast cancer. Women recalled the emotional side of the entire cancer experience. She remembered how other women had to deal with breast cancer and overcome it, and all the emotional struggles they encounter along the way. Some of the toll is from personalizing, wondering could this happen to me. For others, the emotional toll comes from frustration either with the person for delaying diagnosis or treatment, frustration with the not always accurate tests or from distrust of the medical community.

Feelings: Women expressed many feelings when they learned of their friend's diagnosis, during her treatment and in response to the outcome. These included feeling sad, scared, shocked, devastated and traumatized. The feelings were described as "heartfelt" and "stressful". "It's so hard for you" is how one woman described her reaction to the shocking news. Sometimes this was because the friend died. "It was devastating for me because she didn't get better". For others the outcome didn't matter. They felt intense shock, real fear and described it as "a scary thing". "The changes in the body, it's very frightening. Seeing what it does, that scares the bejeezus out of you. Psychologically it's hard on women." One woman expressed mixed feelings upon her friend's death – "shock and sadness when she died, but joyfulness too".

**Feeling her pain:** Having a friend with breast cancer caused many women pain. The pain is different from that of their friend who is undergoing treatment and so forth, but it is real. "I felt her suffering on a daily basis" is how one woman expressed this experience. "It hurts me." Another felt helpless because she could not "help the person alleviate some of the pain that they're going through."

**Fearing it could be me:** Several women felt personally threatened because their friend has breast cancer and they are much like their friend. If it can affect her, why not me? Could I be that brave? It "was a bit of a shock as she is my age, which is fairly young I think" is how one woman described her reaction. Another said, "You know death is imminent and you're seeing someone die before your eyes and you're saying 'It could be me, I'm close to her age.'"

**Never forgetting:** The feelings were long lasting. As one woman phrased it, "It's something that sticks in your mind, you can never forget." This was true regardless if the friend lived, died or did well during treatment. So the consequences of the impact of a friend's breast cancer are permanent. While she may find a way to work through the feelings, she may not and therefore keep recycling her emotions.

#### *DOMAIN 2: Learning from my friend*

Women learned from their experience with their friend's breast cancer. This included more knowledge of the disease and that you can survive. This reduced the woman's fear. Several women were motivated to keep up with their breast exams, mentioning mammograms, self-exams and physicals with the doctor.

**Knowing you can survive:** "Because of this person I have become more knowledgeable." "It just gives you the courage to not be in such denial. It's a new found courage, or stepping stone for us females – of understanding the disease itself a little bit, the steps that we go through, through the pain and all the agony and suffering, all the harsh medications."

**Becoming less afraid:** One woman found her friend's experience helped to reduce her fear of breast cancer. "That's why, I can truthfully say I'm not as afraid of cancer now as if I would've been if this hadn't happened in my family. I believe that if I was to go to the doctor and the doctor says 'Well, Miss, you have cancer'. If he told me that, but it (was) detected early, I would not be afraid of treatment."

**Keeping up with my check-ups, mammograms and self-exams:** Several women were motivated to have breast exams as a result of their friend's experience with breast cancer. "It just made me more aware to keep in contact with myself." "It makes me more concerned and wanna (sic) make sure I do my breast exams, and make sure I take care of myself and my mammograms."

**Realizing how precious life is:** Several women found the experience made them sit back and take stock of life, assessing what is really important. They said "We realized how precious life is and how things that we really think are important, they're not that important. Things that we think are unimportant are really important."

#### *DOMAIN 3: Finding it early*

Many women said mammograms, checking yourself and going to the doctor for exams let a woman know in advance at a point where breast cancer may not be so bad. They *strongly* recommended mammograms to their friends, yet often chose not to have a mammogram themselves. Breast cancer was described as being "subtle – it could be there without your knowledge" – so having a mammogram is important. "She's still in limbo without it." The exams, while not preventing a woman from getting breast cancer, would provide early detection

of any problems. Early detection would allow women to "know ahead of time what's going on with their body. You could nip it in the bud right then. To sustain your life."

Having a mammogram: Recommending their friend have a mammogram was mentioned many times. "I would tell them that they need to have a mammogram every year." "Don't wait, make sure you get a mammogram". "Mammogram is real important." While giving this advice very emphatically to their friends, most of the women in the study decided not to have mammograms themselves. "I would suggest, now this I feel (is) a little hypocritical, but I would suggest that they have mammograms." Mammograms are described as helping to find breast cancer early. Mammograms, "it keeps you, not from getting it, but it'll let you know if you it in advance, where it won't get too bad."

Checking your breasts: Doing breast self-exam was strongly suggested and supported because "you know when there is something not right about your own body." Many specific instructions were given about how to do the exam and what to look for. "Start feeling your breasts, I think it's like clockwise. Go take your bra off and stand in the mirror. Check yourself for lumps. You put your arms up, if you're laying down you put your arm behind your head and you go around for any unusual lumps or bumps. Definitely check every month for any kind of soreness, any type of growth. Are the nipples inverted inside? Can you touch your nipples and twirl them in your finger? Is there any discomfort? Any discoloration? Pain, any sore type of pimple or something on you?"

Getting regular check-ups: Keeping regular appointments with the doctor was recommended to friends. This was suggested less often than getting mammograms or doing breast self-exams. "I think it's very important for ladies to have their physicals." "I think dat, if you go to de doctor then, sometime you can find it early."

Getting checked sometimes: Several women said they sporadically had mammograms and didn't feel a need for more because the tests were always fine. "I'm not really that concerned about doing a mammogram. Why continue to go when it's gonna be alright. Nothin's changed. I don't feel different. Am I going too much?" Similarly women suggested they don't do self-exams as often as they feel they should. "I don't do it on a regular basis." "I don't check my breasts (or) my breast exams like I should."

Getting help: Once a problem is identified the women really wanted their friends to get help right away because cancer will spread and "early treatment is always best." One woman frankly stated, "If you suspect something take your butt to the doctor." "I'd tell her to go immediately and get it taken care of."

Getting mad when women don't seek treatment: Several of the friends with cancer did not seek care when they found out and the women expressed anger. "My friend and colleague, she had a lump on her breast and she didn't go to the doctor. I just get so mad, how people with money and people with no money, they don't do what they're supposed to do." One mentioned a friend who died because "she didn't get checked like she was supposed to."

Being afraid of finding out: One woman discussed in depth her fear of breast cancer and how it caused her to delay getting a breast biopsy. "Fear of what I have experienced by hearing what other people had to say, I was scared to do it (biopsy). I know it's just fear, it's fear from other people that don't live." Several women did not get mammograms or check-ups because of the fear of breast cancer, which to them meant dying a painful death and not seeing their children grow up. "

#### *DOMAIN 4: Increasing your risk*

There was a strong need or desire to explain what causes breast cancer, why this happened to their friend and who is more at risk. "Why does one person get it and I don't?" Not having an explanation is very uncomfortable. "I'm wrong, but I have some kind of answer for myself, OK?" Numerous things were suggested that increased a woman's risk of breast cancer, i.e., lifestyle, being large breasted, exposure to chemicals, family history, bumping the breast, not breastfeeding and destiny. One woman suggested a virus is the cause. Several women said breast cancer "just doesn't seem to be that prevalent in the Black community. You always hear about more prevalent in the White community, other than Black community." Several women said they felt safe from breast cancer because "it's not in my family."

Not understanding breast cancer: "I just wonder where did it come from? How did she get it? Why did this happen? I don't understand all the issues around it. I don't understand it."

Being caused by lifestyle and what we eat: "I do believe all our diseases come from our lifestyle and what we eat. Sometimes I wonder if it's the food that we're eating, because it's in all parts of the body." Eating a lot of "fat, sodium. It might have something to do with our diet."

Being exposed in the environment and chemicals: "I know chemicals have a lot to do with it. They say a lot (of) estrogen cause breast cancer. We lived in the south and they sprayed all these chemicals. I think chemicals or something like that" cause breast cancer.

Smoking: Two views were suggested regarding smoking. Several women said, "I know I can get breast cancer by smoking." Another believed smoking would not be harmful. "I just think that since I've been smoking for so long that my body is just so used to it that cancer just wouldn't exist in my body."

Having a negative mentality: The impact of mental health on physical health was mentioned. "People with really bad attitudes, there's things that happen in your body chemically that can help to cause the cancer. Just from my stroke of somebody, I can cause certain chemicals to be activated."

Having a family history: "It's hereditary." Several women mentioned family history as an important factor for risk of breast cancer. "I think if it's in your family then it's unavoidable. A high risk to me is whether or not you have an aunt, or sister, or mom, or great-grandparent that had this disease. I think it's partly designed, certain things that you're born (with) are just part of you and it manifests later in life. Ask her to look back and see if anyone in her family has had it to make her more aware as to how threatened she needs to be of it depending on how aggressive it is in her family." One person was surprised her friend had breast cancer because "it was not a part of her family history."

Injuring my breast: Some respondents indicated injuring the breasts causes risk of breast cancer. "I think bumps and things" cause breast cancer. "Maybe you have a mate that's rough with you in lovemaking. When you get hit in the breasts too much or injure your breasts in any way, it (cancer) can happen. I run into the wall one too many times, it starts a bruise and the bruise grows and festers and I do know that." Wearing an under-wire bra was mentioned as increasing risk to injuring the breast.

Being large breasted: Having large breasts was related to increased risk of breast cancer. "The one thing I know that the way it happens usually happens to women with large breasts. I'm very top heavy myself and she (friend with breast cancer) was too."

Not breastfeeding: "Women who don't breastfeed (increase cancer risk)."

Coming from the air: Air is involved in two ways – it can cause breast cancer and cause cancer to spread. "Even if it's not cancer, if they cut you and air gets there then you could end up basically having cancer." Other women suggested, "I've been told that once you open up the

body that has it (cancer) in it, it spreads it faster. I should never have let them cut me. She said she felt that by air, when they cut you and do the biopsy by air getting into the cells it would cause it to spread."

Getting older: "As you get older you were more prevalent for cancer" was mentioned as increasing risk by one person. Yet, several others said, "Young women can get cancer just like old women. (Cancer) could come at any age."

Meeting your destiny: Luck or destiny determined if a woman gets breast cancer. "Luck. It's just the odds. If that's the disease you're supposed to get in your life, then you gonna (sic) have breast cancer, but if it's not, then you won't. We all get our dish (sic)."

Feeling safe from breast cancer: Several women said they feel safe from breast cancer because it "is not in my family. I've been blessed with good genes. My mother and grandmothers didn't have it." One woman reported she felt a lot better "after a work-up at a cancer center" and found she "is not prone for breast cancer."

#### *DOMAIN 5: Protecting yourself from breast cancer*

Many interviewees mentioned taking care of yourself to prevent getting breast cancer. Specific suggestions were live healthy, have a healthy outlook, exercise, healthy eating, going for check-ups, getting mammograms, checking your breasts, breastfeeding and taking vitamins. Other women said there is no direct causal relationship between breast cancer and diet, exercise, smoking, large breasts, breastfeeding, healthy eating, taking vitamins and being healthy. Breast cancer cannot be prevented in this way. "I don't think anything keeps me from getting breast cancer." Some women suggested ways to protect you from breast cancer and also mentioned discrepancies. Women who had exams or checked their breasts could still have breast cancer. "I check my breasts. I don't think that's going to do it. I think you can overlook things." "My sister, she's a health fanatic. She takes vitamins and she does all those things and she got breast cancer."

Getting check-ups: "What keeps me personally from getting breast cancer is I go for check-ups every year. Make sure they go for their regular exams and check-ups."

Getting mammograms: Many women said "Mammograms prevent you from having cancer."

Checking yourself: "I examine my breasts. I'm aware of my body and what goes on and what I do. I know my body better than anybody else. You know when there's something not right about your own body." Some women said "I don't do it as often as I should, but I examine my breasts." Another said she knows she should examine her breasts, but she doesn't.

Taking care of yourself: "How you take care of yourself and what (you) do" is the key to protecting yourself from breast cancer. "I try to live a healthy life." Specific suggestions were – "make sure you don't have high blood pressure, lower your cholesterol, healthy eating, lots of vegetables and fruit (all fresh), don't eat food with a lot of white sugar and exercise." "I take care of myself by walking." Several women mentioned having a healthy outlook. "There is such a mind-body connection. I've heard that people laugh and certain things happen chemically inside your body. I tell myself I'm not going to have it (breast cancer). I'm not going to get it. I see positive things into my life. Try and live a stress-free life."

Breastfeeding: "I really do think that there's a connection between naturally nourishing your child and susceptibility to breast cancer. I figure I might be on this 1% that don't get it (breast cancer). I breastfed my last two kids, so that gave me one up."

Taking vitamins: "I take my vitamins." Several women said they take supplements like elderberry for the flu and vitamins and these help protect against cancer.

**Protecting my breasts:** Protecting the breasts from injury was mentioned by several women as key to preventing cancer. "I wear sports bras so I always make sure that I am protected. I used to wrestle with my son, but you can't hit me, you can't push me now. Don't let anyone mistreat you like that, don't let men hit you on your breasts. (I always) be protected with myself because my breast is large."

Nothing can keep me from getting breast cancer: "It (breast cancer) is a nondiscriminatory (sic) kind of disease. I don't think I am exempt from getting breast cancer. I don't know if there's anything that can keep you personally from not getting it. People that have been healthy all their lives are able to get it. Those women that breastfeed and don't have large breasts, they still get cancer too. People who have the exams, people who don't have the exams, people who smoke, people who don't smoke, people who eat real healthy, it just seems like everybody's getting cancer. I quit smoking 18 years ago, but who's to say smoke causes breast cancer? So I don't know what, if healthy eating, really taking care of yourself would exonerate you from cancer. My sister, she's a health fanatic. She takes vitamins and she does all those things and she got breast cancer."

#### *DOMAIN 6: Looking to God*

Many women mentioned God's role. Some believed God's will determines who gets breast cancer and who does not. "The Lord watches me." God also helps heal, treat and support women with breast cancer and their friends.

Keeping me from getting it: "To be truthful, I think God keeps me from getting anything. My faith in Jesus Christ (protects me). Knowing him, knowing that he's true to his word. I guess breast cancer is not something that belongs to me."

Being God's will: Several women said getting breast cancer is God's will. "It's a part of life, it would be God's will. I hope it don (sic) happen, but He had a plan for everybody. I just don (sic) know why He pick and choose. It's not that He means to single you out, it's no curse, it's just something we as females go through. Not all of us females thank God. He has the final say."

Taking care of breast cancer: "You have to turn up to God and let Him take care of it because we can't take care of it. You can only address it to the Lord since the doctors don't have an answer." Women said God helps heal, treat and support women with breast cancer and their friends. "As one of Jehovah's Witnesses, I have a belief that really sustains me through whatever comes my way. I would have to pray." Another interviewee said, "You just can't do that (leave it to God). God might take you to the doctor, but He's not going to heal it."

#### *DOMAIN 7: Getting cancer treatment*

Women discussed at great length the impact of having a breast removed. Will it be overwhelming, a relief or not matter a bit if it saves my life? "It's probably that most women they feel a little different." One respondent was deeply concerned that if she lost a breast, her husband would leave her and she would no longer view herself as a real woman. She did not follow-up on a breast problem because of this concern. Others said having a mastectomy was not really a problem. It was more important to save your life. The most descriptive text was about chemotherapy – causing hair loss and sickness. Several women said they would not have any treatment, one due to her pregnancy. One took an herbal treatment instead of chemotherapy and surgery. Many respondents described their friends as being strong and wondered if they had breast cancer, would be as strong.

Losing a breast: "She had a total mastectomy. They remove your breast." There was a wide range of impact from the mastectomy. Some respondents said, "You have a breast there

and then there's nothing there. Your breast is gone because of this. It is painful that you have your breast removed. I wonder if you miss it. It is actually a part of you is missing and it's an overwhelming change." Others said there was not that much of an impact. "The breast is something that we use, but it's not that functional like our arms and our legs. It doesn't make you less of a woman or anything. It doesn't take away your femininity. It's not all that bad. It doesn't seem to bother her that she just only has one breast. She doesn't mind talking freely to people about it." Some were very strong in their comments. "I don't care about breasts honey. If it saves my life, fine, so I can live. I don't care. It's a relief in a way. You're relieved from the undergarments such as having to buy a bra for this dress or this shirt." That some women had a lumpectomy was mentioned, but most discussion was about those who had a mastectomy. Several respondents said their friends were getting breast replacements.

Losing a body part you see all the time: "I know that breasts is not the only reason why she is a woman. I've thought about this personally, I wouldn't be a real woman anymore if I didn't have my breasts. I think because there is so much emphasis on femininity wrapped around our breasts. (The breast) is a part of your body that you're really happy with and you see all the time. You get up and you don't see that breast. It's not a pretty thing to look at (mastectomy). She went through the thing where she couldn't look in the mirror. I think it's a more obvious thing. Nobody knows if someone has a hysterectomy even if they don't want to have any children. I broke my hand (in a car accident) and that was different. Those were two physical crises, health things that came up, but it's not the same thing." Losing a breast is different.

Worrying about family's reactions: "I guess it's what people are going to say. What they're going to say about you." Most of the concern was about what her partner would think and do. "Even then, at that moment, in my mind, I started thinking about that lump. I never had it followed, I hadn't had a mammogram, so what would happen? If I did have cancer, he'd probably leave me. It seems like their spouses sometimes don't know (how) to respond to them after they had had breast cancer or a breast removed. They're treated differently. I don't mean this in a bad way, but I just think men of color are not as supportive. If I had a mastectomy, I probably never would get married." Others said the spouse would be fine. I'm getting married in July and I think about your mate, will they accept it (if I had mastectomy). Being the person that he is, I don't think it will make a difference. But I've seen movies where the husband or the boyfriend can't deal with it. They leave them. But I don't worry about him (fiancé). He's the type of person that it wouldn't matter to him."

Fighting the disease: "You have to be head strong and heart strong. Your mind does control your body, so you just really say 'I'm fighting this.' Just go stubborn. They dug their heels in. This is where I'm going out of here and this is what I'm going to do."

Going through chemotherapy: Women used powerful words to describe chemotherapy. "Chemo kills everything. She lost all her hair, her eyebrows (and) her eyelashes from the treatment. At the time I was getting married and (thought) if I do chemo this is really going to alleviate my chances (of having children). It did. I saw her so sick from chemotherapy. My sister-in-law, I used to see her go through like withdrawals. I'd go see her in the morning (and) she's just perky and spunky. But then she'd have her chemotherapy done and she would be drained. I had to watch her go through chemo." Some respondents said, "She didn't have any kind of sickness or anything from the chemo."

Refusing treatment: "She refused to get any type of treatment on her breast because she was having a baby." One woman said, "If I personally found out that I had some form of it

(breast cancer), I wouldn't have any treatment or anything done. I'll just keep living with it. I wouldn't do it, surgery." Another's friend decided to refuse chemotherapy and surgery and treat the cancer with herbs.

#### *DOMAIN 8: Helping my friend*

There was in depth discussion about the right way to help a friend with breast cancer. The primary point was to treat the friend the same as before – with respect and dignity – and to accept her as you used to before breast cancer. Many women emphasized telling her to be strong and going through it together. One made a poignant statement about her friend "looking for something from me that I didn't know how to give." Others observed that their friends had to "regroup" as a person after having cancer.

Treating her the same as before: "I hope I never treat anyone different because they got a disease. I'll try to treat you just like I've always treated you. Try to keep people with respect and dignity. She was looking for me to accept her as she used to be before. It was my great impulse to just go, 'Oh, I gotta (sic) go do this, I gotta (sic) go help.' But then I got it in my brains, this person don't wanna (sic) be babied, they want to be able to function and feel like they a whole person. If you see they really in some danger, then you make sure you help. But don't go puttin' (sic) yourself on the person. If they don't ask for help, leave it alone."

Helping the best way you can: "Try and help 'em (sic) the best way you can. That's part of friendship. You're givin' (sic) the person a lot of your time and your energy.

Going though it together: Women spoke about how they would go through the cancer together. "We'll see this thing through together. I will be that shoulder to cry on if you need to cry anytime. If you need to pray, call me, we can pray together. We're always there to support one another. We would talk."

Telling her to be strong: Many respondents spoke about telling stories about how you made it through, how you had courage, faith and fear. "You will survive. It doesn't necessarily mean that you're terminal. Be strong. Keep good spirits."

Trying to be strong for her: Some women said they "You try to draw strength and give strength to a person like this that's going through this."

Looking for something I didn't know how to give: One woman spoke of her friend looking for something too deep. Sometimes you cannot provide what your friend needs. This is all right. "It's like she was looking for something from me that I didn't know how to give. She was needing something from me that I didn't know whether I could deliver. It was kinda (sic) hard for me to make conversation without getting' (sic) really compassionate, really deep, deep compassionate." This friend said "It's nothing wrong with (sic) you." But she "understood that deep within, so made sure she (her friend) never saw that."

Regrouping yourself as a person: Respondents said that getting cancer means "you're blind, you wouldn't be able to see so like they have to start all over. You'd have to start all the way over back again as a person, build their self-esteem up again in order to live again."

#### *DOMAIN 9: Getting poor medical care*

Three areas of concern surfaced regarding medical care. Having a mammogram was one area. This included both excruciating physical pain during the mammogram, as well as emotional pain from the technician's reaction to her breasts, which are different sizes. Believing that health care is geared towards Caucasians and people with money was a strong belief among several respondents. It was strongly felt that the medical community did not know as much about African Americans health issues. There was limited research, less ability to detect cancer and less specialized knowledge of health issues such as sickle cell disease, stroke and high blood

pressure that are more prevalent in the African American community. In addition, one respondent felt strongly that health care services are meted out based on a person's income. The best treatment is provided to women with higher incomes. Yet she believes treatment should be provided equitably across all women regardless of income.

Having a mammogram: "The mammogram hurts. It really hurts. I know that it hurts me with small breasts, I can just imagine what it feels like with women that have large breasts." Another woman was "half disappointed because it didn't hurt. I thought well, maybe it was because I didn't have these big enough breasts." She felt self-doubt. One respondent expressed emotional pain from embarrassment. Her breasts are different sizes. The technician said, "Has it always been like that? Are you okay? Well, we may have to take more pictures of this one because it's bigger than the other one." The respondent said, "It was just funny the way she stopped and looked like this for a whole minute."

Knowing less about African Americans: "Medicine is geared towards Caucasian health problems and not the African American community. I hear a lot about in the medical field that they're really not prepared to deal with African American problems. They have trouble detecting breast cancer in African American women because of the density. It's kind of scary out there to find a doctor that can relate to African American health issues." In addition to not trusting in the medical community knowledge and skills there is note that "There isn't a lot being researched and done about these things." Finally one respondent reported difficulty finding a provider that would listen to her and believe she knows her body. "From my experiences with doctors, I know my body and I try and tell them and they just kind of brush off. I just choose sometimes not to even deal with it because it's stressful and it's frustrating."

Having money means you live: "I don't know if they have certain treatments for certain people. You got the money to live. You don't have the money you won't live. Which I think is BS. You shouldn't be put on a scale for if you can afford to be treated or not. Somebody poor and has breast cancer should get the same treatment as somebody that's rich. I hope my sister's not in that category (poor and receiving poor treatment)."

## DISCUSSION

The impact that knowing someone with breast cancer has on valued relationships with friends, relatives, co-workers and acquaintances is striking, challenging, memorable and often difficult. It is primarily emotional impact and it is long remembered regardless if the person lived, died, did well during treatment or was a survivor. Some of the toll is from personalizing – wondering could this happen to me, could I be that brave? Other comes from being emotionally available and supportive during the friend's diagnosis and treatment. This is draining.

There is a process that women move through during their friend's breast cancer. It includes the shock of learning of the diagnosis, a series of emotional ups and downs during treatment (and perhaps death), acceptance of a friend as she used to be before breast cancer even though she is now different. It challenges women's emotional depths - her ability to face her own fears and concerns about breast cancer. How would she handle it if she had breast cancer and would she die? As she is wondering about these concerns for herself, she must reach to depths to help her friend after the diagnosis, during phases of treatment and afterward as they move to a new normal: a friend perhaps without a breast who survived or a memory of a friend who died. Facing those fears and reaching past them to stay connected, give support and be a true friend is very challenging and takes an emotional and physical toll. It is as though the respondents are "along for the ride" on a roller coaster, a ride that perhaps approaches the degree

of difficulty experienced by the woman with breast cancer. For the friend is watching someone close to her suffer both emotional and physical pain. Being able to open one's self to that pain and reach beyond personal fears to give support is what these friends have done.

Knowing someone with breast cancer also opens many inquiries and explorations of beliefs about what causes breast cancer and subsequently how to prevent it. There are two schools of thought: you can do something to prevent or reduce your risk of getting breast cancer and there is nothing you can do to avoid getting breast cancer. It all depends on what women believe causes breast cancer. Those that believe it is possible to prevent or reduce risk suggest to their friends many ways to take care of yourself, including healthy diet, exercise, stop smoking, breastfeeding, avoiding bumping the breasts, checking yourself, getting regular check-ups with the doctor including mammograms. Yet most of the women do not follow their own advice. They decided not to have mammograms, for example. For some this decision is based on fear of breast cancer – they do not want to die a painful death or not be able to watch children grow up. For others who were sporadic in getting tests they did so because the tests were always fine, so why bother repeating mammograms all the time?

Some women believe mammograms and clinical breast exams actually prevent breast cancer from developing, while others believe these methods help find breast cancer early when it is not so bad.

Those that don't believe you can prevent breast cancer suggest that it is indiscriminant and there is no causal relationship between breast cancer and diet, exercise and so forth. They cite examples of women who live healthy lives and still get breast cancer. Other beliefs about the cause of breast cancer include chance, the will of God, having large breasts and heredity.

The specter of getting poor medical care is also raised through knowing someone with breast cancer. Women believe that friends may receive poor care because they mistrust the providers' limited knowledge of health care issues for African Americans. Several examples of poor mammogram service including a technician who commented rudely about a woman's different sized breasts and several who gave painful mammograms reinforce the critical need for training. Technicians must be experts in providing culturally appropriate and sensitive care that assures women have positive experiences. Providing pain-free mammograms is also a skill that every technician must master. There is no room for the belief that mammograms are painful or the expectation that women be "good patients" and "grin and bear it (the pain)".

Perhaps most shocking is the belief that having money means you live because you receive better care. While this goes against the notion that everyone should have equal access to health care regardless of the ability to pay, it is actually born out in studies that show health and access to care is strongly related to income. So, some women who are poor and African American expect to receive poor care from provider's ill informed about African American health issues. This indicates a need to enhance the knowledge level and cultural competency of practitioners. Even those who have excellent knowledge and skills need training in how to bridge the chasm between the clients' expectation of poor and inappropriate care and the actual care they will provide.

Finally, for some women there were benefits from knowing someone with breast cancer. They learned from their friends that one can survive breast cancer and gained renewed appreciation that life if precious. A key impact for some is they became less afraid of breast cancer and more motivated to keep up with mammograms, clinical breast exams and self-breast exams.

It would be very helpful to know more about why some women were motivated to have breast cancer screening while others had the opposite reaction. Breast cancer education programs frequently use breast cancer survivors as role models to motivate women to be screened. Clearly this technique is destructive for many of the women in this study, yet it would be constructive for a few.

**Appendix: Example of Transcribed Text for Question, What do you think about when you think about taking care of yourself as a woman?**

NOTE: "sic" denotes that the word before the term was typed verbatim from the audio-recording, even though it is not grammatically correct.

PE: Okay, so when you think about... thank you... taking care of yourself as a woman, what do you think about?

W: Priority. Um, even though I'm a large woman, I'm very health conscious, and I take all my different little tests – like my cholesterol is excellent. They say it belongs to a person who's 20, instead of 40–, almost 49, and, uh, I mean 'cause (sic) when I am a health... I mean there's nothing else... I, you can function. You know, so it's priority [inaudible].

PE: Okay, great. When you hear the word "cancer," what do you think of?

W: Cancer is a disease that eats you from the inside. Um, it's very less likely to control or to eradicate, even though they have a lot of chemotherapy. But even though it goes into remission, it's just something that lays dormant 'til (sic) it seem to come back, and ki–, constantly haunt you. I've had too many friends, and, uh, other relatives who have died of different forms of cancers. And it just, it's, like, to me, it's like AIDS – something that's incurable. You know, they just put it on hold for a little while. But it's incurable. It's a ugly disease.

PE: When you say it "eats you from the inside," what do you mean by that?

W: Uh, like it starts with crushing different, you know, like your spine. It depend on when the cancer's located. It just crush, it, it, uh, tears it up, eats it up, you know, gets rid of certain bodily functions inside. Like your pancreas, your, your spine, your brain, uh, it deteriorates (sic) all those different things. That's my way of saying "eatin' (sic) it up:" "It deteriorates" (sic). Yeah, and so, you're no longer being able to function with those different vital organs. Mmhmm.

PE: Okay. When you hear the word "breast cancer," what comes to mind for you?

W: Havin' (sic) no more boobs. Your bras's (sic) fit differently. Uh, less attractive. Uh, as far as physical form, something that develop with you as a girl, and you grow up as a woman, and now you no longer will have them. Uh, one or the other. Uh, absence of body and state of mind. Mmhmm.

PE: In what way, uh, is it absence of state of mind or does it affect your state of mind?

W: Uh, because you've lost something that's been a part of you from, from growing into it. You grew into them, and you either, one way or the other, have to lose them. So, you're losing a part of your personal self. So, it's, it, it, it takes a mental toll in order to accept, first, that you have it, and then secondly, if you have to lose them. So, it's just like losing

any-, like a child. It's a part of you, it's attached to you, you know. And, in that form. Mmhmm.

PE: Okay, what is your personal experience with someone who has had breast cancer?

W: [woman sighs] Hmmm. Very traumatic. Um, mostly just very traumatic. Uh, very heartfelt, um, a lot of prayers, a lot of consoling, a lot more prayers, and a lot more consoling. Um, it, it takes a lot of, out of you mentally. You know, and then it pull-, tolls on you physically 'cause (sic) you're givin' (sic) the person a lot of your time, you know, and your energy. And, uh, being, that's friendship. That's, part, part of friendship, you know. It just really takes a toll on you emotionally. 'Specially (sic) when you have a friend you've known quite a bit of your life, and they have to lose a breast or both breasts, you know. Mmhmm. And the emptiness they feel is you're sharing it with them. Mmhmm. Yeah.

PE: What way is it "traumatic?"

W: Well, just, what I just said. The idea of they have to lose what's part of them, or what's attached to them. And, you know, it's a, a different form of a amputee (sic). You know, 'cause (sic) that's what's being done, they're being removed just like a limb. Sumin' (sic) that was useful. You know. Mmhmm.

PE: Okay, thank you. Uh, what story comes to mind for you when you think about the words "breast cancer?"

W: No, um, no real particular story because I've had so many different friends or associates who've, who've had breast cancer, you know. Just a matter of them going to doctors and calling me later, and, what has happened, and them asking me to pray for them. You know, and, and what's the best way to keep a stable mind about it, you know. And their main thought and concern is being attracted (sic) to the opposite sex. Or if they're, or in the same gender res-, relationship to the same sex, you know. And that's part of their main concern – that no one will desire them because it's been gone, you know. And, those are, the stories are all pretty much the same because they pretty much have the same because they pretty much have the same ideas and notions about 'em (sic).

PE: Okay. Okay, thank you. Uh, what do you think keeps you personally from getting breast cancer?

W: Personally, I, I, you know, I really don't know. I, I think it's partly designed, certain things you're, that when you're born are just a part of you, and it manifests later in life. You know, um, certain things, chromosomes, genes, or whatever. [inaudible] there are family members who have ca-, cancer that are female but not breast. They've been other parts of the body. And so, which I make sure I keep a close eye on those different areas. Um, mainly, I just think it's just certain old things that you're born that either determine what may come out of natural causes other than natural causes, you know, uh, to have breast cancer. Yeah.

PE: Okay, thank you. If you were to tell your best friend about breast cancer, what would you say?

W: Uh, just as far as when you say to tell her about it, in what, what realm of telling her?

PE: Well, in whatever, in whatever realm you, you wanna (sic) answer it in, if your friend needs some advice, wanted to know what you knew about breast cancer.

W: My, my, my only thing as far as knowledge of breast cancer is keep your mammograms depending on your age. If you're over 40, least have one, uh, every two years. Uh, getting closer to 50, maybe every other year. And whatever the doctor informs you of based on your age. And, uh, just to watch for it and do your own personal breast examinations, and, um, 'cause (sic) it can go in different areas of the body. Just because it appears in the breast it can travel and go someplace else. So, my main concern is just do your own self-examinations. You have concerns, always address it to your gynecologist or whoever your, your doctor may be. Yeah, and um, even though I, I do mention it to my friends, I just, I say, "Have you had [inaudible] breast exam?" "Why you always ask me that?" I say, "'cause (sic) it's important." Yeah, I mean, just, you, you get cancer in all different parts of our bodies. You know, so it's important to be concerned about that part of your body as well as any other part. You know, hard is wonderful, but you gotta (sic) be concerned about the breasts, your vaginal area, it, your brain [woman laughing] – all of it. You know, it's your body, it's your self, be concerned. And so that's mainly how I would discuss it or the issue ever arised (sic), yeah.

PE: Okay. What are the greatest fears, if any, that you have about breast cancer?

W: [woman sighs] Fears. Actually, I really don't fear it to be honest, 'cause (sic) I've dealt with it so much. It's not a fear, it's just something that's unpleasant. And, um, mostly just unpleasant, and it just causes a lot of different domino theories to go on with the individual. First, the fact of them accepting what's gone on with them. First, to deal with family members and their spouses. And just to try to find a way to live life fully, because of that part of the body, you know. So, I, I really don't fear... I don't... All this should pass away, so I don't fear it. You know, you have to deal with whatever comes along in life and just deal with the issue at that time. You know, so, I mean I think the fear of fear itself [woman chuckling].

PE: Okay. In your own words, what is a "mammogram?"

W: Um, takin' (sic) a X-ray of the breasts, uh, to find out if there are any cancericks (sic) tissues, uh, in the breasts. Uh, in, uh, [inaudible], exactly what it is in the mammograms. In the, in the, I can't pronounce the word. But, uh, to, they're looking at the tissues in different areas on different angles to make sure there isn't anything that has grown or developed in the breast that shouldn't be there. Mmhmm.

PE: Okay. Uh, what does a mammogram do for you, if anything?

W: Um, detect early signs of cancer. Yeah. Basically all it does. Just to detect early signs of cancer, or it may see cysts or things, anything abnormal, and, or, abnormalities (sic) in the breast. Uh-huh.

PE: Okay. What problems, if any, come from having a mammogram?

W: Problems? Well, maybe soreness. Yeah, 'cause (sic) they squish ya (sic) a lot [woman laughing]. They squish ya (sic), and put ya (sic) in some very unique positions. So, I, that's the only problem I can see. If they can find a way to do it where it would be less discomforting would be wonderful. Yeah, but that, that would be the only problem I could see in it.

PE: Okay. Uh, what is the worst thing you can imagine if you were to be diagnosed with breast cancer?

W: Well, the only worst thing would be you have to have 'em (sic) both removed. Both breasts removed. And, that would be the worst thing is to have 'em (sic) both removed. And beyond having them removed, if it'd spread through other parts of your body. And that would be the worst thing. Mmhmm.

PE: Mmkay. So why did you decide to not get a free mammogram when it was offered to you?

W: Um, 'cause (sic) it, it just depends on what was going on. If I'd just lost a loved one, or that would probably been the only reason. I was probably was in a unique state of mind. I really wasn't caring at that time. I had too many other things to deal with, and I believe that's what it was. Uh, I had lost. That's when I lost both of my aunts in a car accident, and they lost their, their heads were decapitated. So, I, I could cared less at that time. Yeah, so that was the only reason, but then later I did go ahead and have one done. Mmhmm.

PE: So you, do you get mammograms yearly, or...

W: Every other year.

PE: Every other year?

W: Mmhmm. Yeah, I'll hit the 50 mark next year, so [woman laughing] it may probably be every year [woman laughing].

PE: Where do you get them done?

W: Uh, up at, uh, Providence.

PE: Providence?

W: Mmhmm. Mmhmm. Yeah.

## **Appendix: Era of Hope Abstract & Poster Presentation, Orlando, Florida**

### **CONDUCTING CASE INTENSIVE INTERVIEWS WITH FISCALLY CHALLENGED AFRICAN AMERICAN WOMEN WHO DECLINED FREE SCREENING MAMMOGRAMS. ACCESS, ACCRUAL, & REFUSAL RATES**

**Frances Marcus Lewis, Ph.D., R.N., Ellen Phillips-Angeles, M.S., Kathryn Bunt, B.A. and  
Lin Song, Ph.D.**

#### **Statement of Problem:**

Breast cancer screening programs hold the greatest promise for early detection of the disease. However, rates of participation in breast cancer screening programs in community-based samples have been disappointing for low income, uninsured African American women. This study describes our experience in accessing and accruing fiscally challenged African American women into a case intensive interview study who were identified from a population data base. All women were eligible for but decided to not obtain a free screening mammogram after outreach into the Breast and Cervical Health Program (BCHP) of Washington state.

#### **Study Methods:**

An initial confidential population database was downloaded to a recruitment intermediary. Detailed spreadsheets were then maintained by the intermediary that enabled us to track the total population of potential study participants, including contact attempts, rate of outreach, enrollment, accrual and refusals. Detailed notes were kept on reasons for refusal. A minimum of 3 contact attempts was made for each woman in the recruitment list; most received 6 contact attempts.

#### **Study Results:**

Table 1 graphically summarizes the main study results, including losses to the study from the initial pool of study participants. The table reads from top to bottom.

The initial population database consisted of 685 eligible women. Of these, 28 were immediately ruled out because no phone number was available for them. Of the remaining 657 women, 290 women (44%) had non-viable phone numbers [wrong phone numbers and out-of-service numbers]. Of the 559 women with potentially viable phone numbers, 175 women (31%) were successfully contacted by the intermediary.

Of the 175 women contacted, 26 women explicitly declined the intermediary's invitation to participate. This small number involved the ONLY women who explicitly refused to participate in this study based on phone contact. This represents an initial refusal rate of only 15 % (26/175).

Of the 175 contacted women, another 91 were screened out as ineligible by the intermediary based on data obtained during the phone contact. The most frequently cited reasons for

ineligibility were the woman's claim that either she had not refused a free mammogram or that she had obtained a mammogram from another source during the time of the outreach by the BCHP outreach worker. This high rate of ineligibility raises questions about three things: the completeness of information stored in the population data base from which this team drew the study sample; recall error; or a self-enhancement or social desirability bias in the woman's response.

A total of 192 additional women had viable phone numbers but, despite repeated contact attempts at different times and on different days, only an answering machine, not a "live" voice answered the call. This represents 52% of the women with viable phone numbers.

A total of 58 women (58/175: 33%) verbally agreed to have the intermediary give their name and phone number to a study team interviewer. Of these 58 women, 9 either declined to be interviewed after the interviewer contacted them to establish an appointment or were screened out by the interviewer as ineligible.

### **Study Conclusions:**

Fiscally challenged African American women, if reached by phone by an unknown intermediary ["cold called"], are willing to participate in studies like the current study. However, diligent attempts to contact them are needed.

Most women were lost to study because of non-functioning phone numbers. Non-functioning phone numbers involved 3 types: the number was no longer in service; the number was in service but was no longer linked with the woman in the population data base; the number was in service but was never answered by a "live" voice, only a message machine.

### **Implications for Future Studies with Population Data Bases:**

- Public health officials need to maintain multiple updated phone contact numbers to protect these women's future participation in studies.
- Prior to initiating contacts to the population database, the phone contact numbers of potential study participants should be verified through additional data sources.
- "Cold calls" by an unknown intermediary, although linked to a low explicit refusal rate, may have a higher *hidden* refusal rate. Namely, women may be using their answering machines or "caller ID" to filter out the contact call attempts from the unknown intermediary.
- Future studies may need to include an intermediary known to the potential study participant. An anonymous intermediary may have limited effectiveness.

**Acknowledgement:** Supported by U.S. Army Medical Research & Materiel Command  
DAMD17-00-1-0493

**Appendix : Interviewer Training Manual for Workshop**

**Interviewer Training Workshop**

**TAKING CARE OF YOURSELF:  
A Study of Factors Influencing African American Women's Participation  
in Breast Cancer Screening**

**Conducted on:  
October 20, 2000  
&  
November 15, 2000  
&  
MAY 10, 2002  
&  
February, 2003**

**Department of Defense Partnership Grant**  
Frances Marcus Lewis, Principal Investigator  
Ellen Phillips-Angeles and Lin Song, Co-Principal Investigators

## **WELCOME & GREETINGS!**

Thank you for participating as members of the interview team on the ***Taking Care of Yourself*** project. It is our pleasure to carry out this study with you.

The purpose of this workshop is to add to your skills and abilities to conduct successful interviews with study participants. At the end of the workshop you will be able to:

1. Analyze verbal and non-verbal behavior that creates a successful interview.
2. Describe at least 5 characteristics of a "successful" interview.
3. Identify common barriers in an interview that keep women from talking.
4. Identify behaviors in yourself that might block or otherwise hinder a woman from talking in an interview.
5. Demonstrate a successful interview that uses a standard set of questions.
6. Obtain signed informed consent.
7. Describe optimum ways to tape record an interview with a study participant.
8. Identify the sequenced steps in the study from contact with potential participant through to completion and filing of interview tape.

A summary of the importance and purpose of the interview study follows. The name of the study is "Taking Care of Yourself."

## ***Taking Care of Yourself***

Breast cancer screening programs offer the greatest promise for early detection of the disease. However, rates of participation in these programs have been extremely disappointing for African American women, for low-income women, and for the uninsured. Early hopes were held for increasing these women's participation in screening programs when Congress passed the Breast and Cervical Cancer Mortality Prevention Act of 1990 (CDC, 1998). Although this program has increased participation rates compared to pre-program levels, success rates are less than ideal. This means that variables other than free services are related to women's choice to participate or not participate. The current proposal assumes that cultural and perceptual factors and beliefs, yet to be elaborated in the research literature, are **factors that affect low participation rates in free breast cancer screening programs for financially challenged and uninsured African American women.**

Prior research on factors that affect utilization rates in screening programs have been biased; data are primarily limited to information obtained from women who participate in a breast cancer screening program. Both clinicians and scientists alike have little scientific information on the factors that affect low income, uninsured African American women's decisions to NOT participate in a breast cancer screening program, even when that program is FREE. Additional research, like that suggested in this proposal, is needed to more fully describe the factors that affect these women's non-utilization of free screening services.

The purpose of the proposed study is to **describe and elaborate the perceptions, beliefs, and culturally embedded meanings that low income, uninsured African American women hold toward breast cancer and breast cancer screening, including mammograms.**

**The training today relates to Phase 1 of the *Taking Care of Yourself* project.** Phase 1 will involve face-to-face interviews with uninsured, low-income African American women. **Phase 2** will involve focus groups in which women will be asked to give us feedback on the things we discover in Phase 1.

The training for today is planned so that you will be able to conduct successful interviews with the women participating in the study. "Successful" interviews are interviews in which each woman offers full descriptions and stories of her own thoughts, views, feelings, and beliefs. "Successful" also means that you will be talking about 1/15<sup>th</sup> of the time compared to the woman being interviewed! That means that for every question you invite her to answer, she gives you, on the average, **15 words for each word you use as an interviewer.**

## **Interview Goals for Grant:**

Case intensive interviews need to be conducted on uninsured, low-income African American women. There are FOUR groups of women we hope to interview:

### **Group:**

Women who refused initial outreach

[Original outreach worker known]

Women who refused their first mammogram

Women who refused at least 1 re-screening,  
but accepted their first mammogram

Women who enrolled in 1996-98, but haven't  
been seen again

## **MODULE 1: Successful Interviewing**

An interview is a professional activity that requires focus. What is said is by the interviewer is purposeful and systematic.

An interview can also be caring and sensitive. We care about what the woman has to say about her experiences with breast cancer and screening. We also care about what the woman has to tell us, no matter what she says.

When we combine both caring and behavior of a "successful" interview, a magic occurs. The magic is that a skilled interviewer is able to stay focused on the interview questions while also helping the woman fully describe what she has to say.

A caring and focused interviewer is most likely to have lengthy descriptions and detailed stories from the woman who is interviewed.

In science, such lengthy description is called "thick description." Such description is a full word picture of what the woman wants to tell you for each question you ask.

Thick description means that the woman speaks in paragraphs when she answers each interview question. Each paragraph becomes a rich set of sentences that best represents each woman's beliefs, thoughts, and feelings.

How can an interviewer assist a woman to fully describe the woman's experiences in an interview? The answer to this question is the focus of Module 1.

### **Listening to Each Other**

Form pairs with each other. In the next 5 minutes, one of you tells the other person about something that has happened to you during the last two weeks that was a difficult situation for you. The other person is the listener. The listener's job is to sit quietly while you tell her about this difficult or important situation. We will tell you when to switch roles after about 5 minutes.

Next, the person who was the talker will become the listener. The person who was the listener becomes the talker.

Your job as listener is to be able to listen to the woman's story and be ready to report it back to her and to us as a group.

Please make pairs and begin.

### **Review of Listening Assignment**

- 1) Report back on what you heard when you listened.
- 2) What did it feel like to be listened to?
- 3) What was difficult for you when you were a deep listener?
- 4) What was comfortable for you when you were listening?

## **Attentive Listening to Each Other**

Attentive listening involves the use of specific verbal and non-verbal behaviors that assist the woman to talk and more fully describe and elaborate her answers to the interview questions.

Being nice and kind are NOT the same as attentive listening. *Attentive listening* involves specific verbal responses and body language. With both verbal and non-verbal body language, the interviewer is communicating to the woman that the woman's words and experience are the most important things to be shared. The focus is on helping the woman fully tell her story and to describe her ideas and views.

### **Examples of non-verbal behavior that show attentive listening include:**

1. Leaning forward toward the woman during the interview
2. Touching, as appropriate, the woman
3. Maintaining eye contact with the woman
4. Facial expressions that reflect attentiveness
5. Using "Mmmm"
6. Nodding your head sympathetically as the woman talks
7. Maintaining a calm facial expression while the woman talks
8. Avoiding non-judgmental movements during an interview, including gasps or frown.

**Let's take some time now to practice a few of these helpful non-verbal behaviors.**

Attentive listening does not involve **social chatter**. **Attentive listening is a purposeful interaction with the woman.** There are differences between a social conversation and a focused interview.

## REHEARSING VERBAL BEHAVIOR FOR A SUCCESSFUL INTERVIEW

Let's take a minute now to observe an interviewer assist a woman to more fully describe and elaborate what the woman tells the interviewer.

**Scenario:** While carrying out the interview, a woman expresses serious concern about her self-worth if she were to find, through mammography, that she had breast cancer.

Specifically, she tells you,

*"I have a lot to loose if they ever find breast cancer in me. I would rather be dead."*

Observe what the interviewer does to assist the woman to more fully elaborate her story.

What did you see or hear the interviewer do to help the woman more fully talk about her thoughts?

**Scenario:** While doing an interview, a woman tells you how she was treated recently at a doctors' office.

Specifically, she says,

*"I felt like they treated me like 'dirt.' I have enough to deal with and don't need no attitude from her."*

Watch and listen again to see what the interviewer does to assist the woman to more fully elaborate her story.

What did you see or hear the interviewer do that helped the woman more describe what happened to her?

## **VERBAL BEHAVIOR FOR AN EFFECTIVE INTERVIEW**

### **To add to the effectiveness of your interview:**

- Ask each question correctly.
- Ask each question slowly and unrushed.
- Offer silence and attentiveness after each question.
- Clarify the question when the woman is struggling with the question.
- Listen for WORDS in the answer that deserve further description.
- Do NOT assume you know what a woman means by "common" words.
- Allow enough time to ask all the interview questions; each is important.
- Use OPEN-ENDED or CLARIFYING questions to help the woman talk.

### **Ask each question correctly.**

- Each question is designed to elicit a specific area of information.
- Do not paraphrase or change a question.
- Ask the question and then sit silently.

### **Ask each question slowly and unrushed.**

- Speak each word of the question clearly to the woman.
- Do not embellish or alter the original question.
- Each question was designed to get at a particular aspect of her story.
- Allow enough time for the woman to think about the question before she answers; don't rush her.

### **Offer silence and attentiveness after asking EACH question.**

Quiet and silence are magic! They tell the woman that you want to listen to her, that what she is about to say deserves your fullest attention.

Sit quietly now and COUNT SLOWLY TO 15; that is the MINIMUM amount of silence that you should offer each women after each question.

### **Clarify the question when the woman is struggling with the question.**

- The words of each question were carefully chosen.
- If a woman does not answer, ask her: Do you want me to repeat the question? If Yes, then repeat it. If No, then sit silently.
- If woman asks you to say what we mean by the question, tell her:  
It is whatever you want it to mean. There is no right nor wrong answer to the question.
- If the woman asks you to clarify the question, then offer the alternative version of the question.

**Listen for WORDS in the answer that deserve further description.**

When a woman uses a term you do not know or which you do not understand, invite her to talk more about the term(s).

**Do NOT assume you know what a woman means by “common” words.**

Remember, you want the woman to paint the fullest picture she can about her experiences.

If she uses common words, do not assume that you know what she means.

Example: A woman says, “Mammography is a machine that squeeze your breasts and cause you pain.” Ask her: What do you mean ‘cause you pain’ OR Can you say more about that? OR What do you mean by ‘squeeze.’

It can be easy to start assuming you know just what the woman is talking about  
When she uses words that you have heard others use before.

For example, “I think the mammogram can cause me to get breast cancer.”

Do not assume, however, that others women’s words have the same meaning as this woman’s words. **We have no idea what she means when she says the mammogram can CAUSE HER TO GET BREAST CANCER.**

**Allow enough time to ask all the interview questions.**

Each question has importance and needs to be asked.

Watch your time so that about half way through the questions you are half way through the length of your appointment time with the woman.

Do not spend all or most of your time on only a part of the questions when you know the goal is to get all of them asked while not rushing the woman.

**Use OPEN-ENDED or CLARIFYING questions to help the woman talk.**

These types of questions require that the woman give you TEXT,  
not a simple Yes or No answer.

See Figure 1 on the next page for examples of open-ended and clarifying questions. Open-ended and clarifying questions help the woman to more fully tell her story.

When you do not understand or when you do not want to assume you understand, invite the woman to talk about it some more.

**For example, Can you tell me what you mean when you say the mammogram can cause you to get breast cancer? OR Can you tell me about that?**

**Table 1 : Open-ended, Clarifying & Other Types of Questions**

	<b>Closed-ended</b>	<b>Open-ended</b>	<b>Clarifying</b>	<b>Leading</b>
When to use:	Use infrequently	As frequently as possible and whenever appropriate.	In response to a reply, as a request for further information.	NEVER!  AVOID USING LEADING QUESTIONS!
Elicits from woman:	Brief and exact reply such as "Yes," "No," "Sometimes," or "I don't know."	Longer reply; demands thought, allows for explanation of feelings and thoughts & concerns.	Explanation of an earlier statement.	Causes woman to answer the interviewer with what she thinks interviewer wants to hear.
Examples:	"How many lumps did you feel?"  "Do you think you'll follow through with changing your plans to be screened?"	"What do you think helps you stay healthy as a woman?"  "What are some of the things a person can do to protect herself from breast cancer?"	"What is difficult about making a mammogram appt?"  "What about mammograms might be dangerous?"	"Are you trying to be a good mother for your children?"  "Isn't finding the breast cancer early better than dying?"

Let's take a few minutes now to walk through examples of these open-ended and clarifying questions in Figure 1.

**What do you notice about the open-ended and clarifying questions?**

**What distinguishes them from Yes or No-type questions?**

**How do you know when you are using a “leading” question?**

## **ADDITIONAL STRATEGIES THAT ENHANCE THE EFFECTIVENESS of an INTERVIEW**

There are ways to maximize the effectiveness of an interview. These "nuggets" for a successful interview are summarized next.

### **Prepare Yourself for Each Interview by:**

1. Reminding yourself of the purpose of the interview.
2. Recalling the importance of having the woman's fullest possible response to each question.
3. Remembering that your skills as an interviewer will help us help the woman's voice be heard!
4. Go over each interview question quietly in your mind; let these questions become part of you. During EACH interview, bring these questions with you, but know them like a musician knows a piece of music.
5. Enter each interview as comfortably and as relaxed and refreshed as possible.

### **During the Interview:**

1. Introduce yourself and the purpose of your time together. See approved script.
2. Comfortably position yourself and the equipment so that a good recording occurs.
3. Maintain eye contact with the woman.
4. Refer to EACH interview question, one at a time. Do NOT skip any question.
5. Think about the woman painting a picture of her ideas onto the taprecorder; you want the fullest and most complete picture she can paint to be recorded.
6. Use SILENCE to tell the woman that what she is sharing is very important to you.
7. Do NOT ask each question too quickly. Allow a few seconds for quiet between each question. This silence allows the woman to hear her own words and to ADD something she might think about during that silence.
8. Use a calm voice, not a "hyper" voice or a "rushed" or "breathless" voice.
9. Remember: YOU ARE THE LEARNER AND THE WOMAN IS THE TEACHER of her story. Your job is to **DISCOVER** the woman's story by helping her tell it.

## **MODULE 2: Common Barriers to Successful Interviewing**

### **Introduction**

Even when you work to help a person share a full description and answers to an interview question, there are ways that we know can block, hinder, or keep the woman from telling you all that she has to say. We call these **barriers** in an interview. Each of us, no matter how many interviews you have done in the past, might create a barrier that keeps the woman from sharing her total thoughts.

The purpose of this module is to help you learn new barriers as well as identify your own personal barriers, the ones that are most likely to occur when you are the interviewer.

There are both VERBAL and NON-VERBAL barriers.

**Take a few minutes now to read through these barriers. We will discuss each one.**

**Table 2: Barriers to Effective Interviewing**

<i>Category of Barriers</i>	<i>Explanation of Category</i>	<i>Examples</i>
False reassurance	Using false, comforting phrases in an attempt to offer reassurance.	"It will be okay." "Everything will work out."
Giving advice	Making a decision for a woman. Offering personal opinions. Telling a woman what to do.	"I feel you should ..." "If I were you, I would ..." "You ought to ..."
False inferences	Making an unsubstantiated assumption about what a woman means. Interpreting the woman's behavior without asking for validation. Jumping to conclusions.	"What you really mean is you don't like your doctor." "You seem to be blaming others for your not getting a mammogram."
Moralizing	Expressing your own values about what is right and wrong, especially on a topic that concerns the woman.	"Not being screened is wrong." "It is wrong to refuse to have the doctor check your breasts."
Value judgments	Conveying your approval or disapproval about the patient's behavior or about what the patient has said. Using words such as "good," "bad," or "nice."	"I'm glad you decided to." "That's a really nice way to behave." "You are a good woman."
Social responses	Polite superficial comments that do not focus on what the patient is feeling or trying to say.	"Isn't that nice?" "Health department rules, you know." "Just do what the doctor says." "It's a beautiful day."
	Use of clichés.	

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**Table 2: Barriers to Effective Interviewing**

<i>Category of Response</i>	<i>Explanation of Category</i>	<i>Examples</i>
Over-talks	Interviewer talks at the same time as patient.	
Interrupts	Interviewer interrupts woman when woman is talking.	
Cheering up talk	Interviewer tries to make woman feel happier during the interview, especially when the woman says something sad.	"Let's think of how wonderful your children are." "Think about how much your family loves you."
Close-ended questions	Interviewer asks "Yes" and "No" questions only.	"Are you sad?," instead of, "Tell me about your sadness."
Over-paraphrasing or summarizing	Interviewer tries to shorten what the person said.	
Personal story sharing	Interviewer tells patient about the interviewer's own experience.	"You remind me of a friend who thought the world would end if she found cancer in her breast."

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**Table 2: Barriers to Effective Interviewing**

<i>Category of Response</i>	<i>Explanation of Category</i>	<i>Examples</i>
Rushing to a solution		"Here is the way to stop thinking that – every time you think those thoughts, pick up your knitting and knit."
Directing the acceptable behavior	Imposing a prescriptive statement	"You should not think about yourself so much. Think about other people instead."
Refocusing or redirecting	Refocusing the discussion away from the sources of tension, either explicitly or implicitly.	"Let's not talk about this anymore." "There is no need to cry about this."

### DEMONSTRATION OF BARRIERS DURING AN INTERVIEW

**Scenario:** While carrying out the interview, a woman expresses serious concern about her self-worth if she were to find, through mammography, that she had breast cancer.

Specifically, she tells you,

*"I have a lot to lose if they ever find breast cancer in me. I would rather be dead."*

Observe what the interviewer does to BLOCK the woman.

### Demonstration of Common Barriers

Return to the list of common barriers on the previous pages. Listen for examples of these barriers in the interview that will be demonstrated for you. When you hear a barrier, mark a checkmark in the appropriate box. If the barrier occurs more than once, make a checkmark each time.

### **MODULE 3: Conducting an Attentive Interview with Clarifying and Open-ended Questions**

Now you have all the pieces to put together to conduct a “successful” interview. The focus of Module 3 is to add to your skills in carrying out a successful interview.

**Form pairs. Using the first three questions of the Interview Schedule, carry out the interview, using the non-verbal and verbal strategies we have reviewed.**

**We will AV tape you; review the tape; and learn together on ways to do successful interviews.**

## **MODULE 4: Obtaining Signed Informed Consent**

The interview is part of the Department of Defense research study. Before the interview is conducted, we are legally required to inform the woman of her rights and must also obtain her signed informed consent before the interview is carried out.

A signed consent form is a legal document; one copy gets filed at the UW Office and the other copy is given to the woman for her own keeping.

**Take a few minutes now to read the Consent Form that is approved for use. It is on the next page. We will discuss the Consent and its important parts after you have first had a chance to read it.**

This means that the woman, prior to being interviewed, must give her informed consent to participate in the interview before the interview is conducted. In practical terms, this means that you will read the consent form to the woman while you are sitting with her.

Our experience is that by reading through the consent form with the woman, you are guaranteeing her the right to hear and understand what the form says. If you tell her to read the form, she may or may not read or understand all the words.

**Watch now and see how the interviewer can comfortably and smoothly do this.**

The woman has the right to:

1. Be introduced to the study using the text to the Consent Form
2. Have an opportunity to ask questions about the study, in advance of the interview being conducted.
3. Be given the right to refuse to participate in the study, even as late as just before The interview is carried out.
4. Be given a copy of the signed consent for her own files.
5. Be able to decline to answer any question during the interview.
6. Be able to stop the interview at any time.

These are her rights.

**Let's take a few minutes now and practice this together in pairs.  
Each of you take turns reading through the consent form with each other; one of  
you be the woman and the other the interviewer. Then, switch and change roles.**

**How did it feel to be the interviewer?**

**How did it feel to be the woman being read to?**

Let's go over a few more points.

1. Read over the Consent Form.
2. What questions do you have about the form?
3. What do you think might be difficult, if anything, for you in helping the woman complete the signed consent form?

## **MODULE 5: Preparing to Tape Record an Interview**

Recording an interview is as important as conducting an interview and there are optimum ways to tape record an interview. The purpose of Module 4 is to teach you how to reliably record an interview even with a soft-spoken woman.

### **Preparing Your Equipment BEFORE Seeing the Woman**

Labeling your audiotape with woman's code number, date of interview, and

Name of interviewer

Recording woman's code number and date on tape before the interview.

### **Testing Your Equipment Prior to the Interview**

Playing back your recorded message on tape, listening for quality of recording.

### **Carrying Back Up Supplies**

Battery Pack

Extra tape [in case of breakage]

### **Signs of Problems**

Chipmunk quality to recorded message

Voice-activated taperecorder cautions

### **Positioning the Tape Recorder/Microphone**

Place the microphone so that it picks up woman's sentences

Plug in taperecorder whenever possible.

Rely on batteries only if electric plug in is not available

## **MODULE 6: Clarifying Each Person's Responsibilities in the Study**

Fran Marcus Lewis: Principal Investigator

Ellen Phillips-Angeles: Co-Principal Investigator

Lin Song: Co-Principal Investigator

### **Interviewers:**

Interviews

Interviewers' Meetings

Contact with Jennifer or Rietta for referrals into interview study

Contact within 2 days or less to women being willing to learn about study

Appointments to interview women

Calling Assistant Research Manager to obtain contact information on the enrolled participant:

Interviewer initially calls woman

Appointment is made to interview woman

When interview has occurred

When tape recording of interview is delivered to UW office

Submitting ground travel reimbursement

Obtaining new tapes for recording interviews as needed

### **Community Advisory Committee**

Meetings are scheduled by Ellen Phillips-Angeles

## **DOD Grant: Telling My Story**

### **Interview for Phase 1**

1. When you think about taking care of yourself as a woman, what do think about?
2. When you hear the word "cancer", what do you think of?
3. When you hear the word "breast cancer," what comes to mind for you?
4. What is your personal experience with someone who has had breast cancer?
5. What story comes to mind for you when you think about the word breast cancer?
6. What do you think keeps you personally from getting breast cancer?
7. If you were to tell your best friend about breast cancer, what would you say?
8. What are the greatest fears, if any, you have about breast cancer?
9. In your own words, what is a mammogram?
10. What does a mammogram do for you, if anything?
11. What problems, if any, come from having a mammogram?
12. What is the worse thing you can imagine if you were to be diagnosed with breast cancer?
13. Why did you decide to not get a free mammogram when it was offered to you?

## **CRITERIA OF A "SUCCESSFUL" INTERVIEW:**

- Each question was asked correctly.
- Each question was asked slowly and was unrushed.
- Silence and attentiveness occurred after each question.
- A question was clarified when the woman struggled with it.
- Interviewer invited elaboration of words of woman that deserve further description.
- Interviewer sought the woman's further description of "common" words.
- Interviewer paced questions so that all the interview questions are asked.
- Interviewer used OPEN-ENDED or CLARIFYING questions to help woman elaborate.
- Tape recorder recorded the woman and interviewer's voices.
- Battery did not cause 'chipmunk' sounds.
- Interview was not interrupted by others or other noises.

### **OTHER:**

***Thank you for coming to the workshop training!***

**We look forward to working closely and learning along with you.**

***Our hope is to accurately capture what women think, believe and feel when they choose to not get a free mammogram.***

## **Appendix: Belief Statements Deductively Derived from Phase 1 Interviews**

Department of Defense Idea Grant

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### **Beliefs about mammograms**

Women believe it's important to pay attention to one's breasts, and get breast exams and mammograms (#200077, lines 151, 259-260).

[Includes a woman must "fight for the right" to get a mammogram (#111112, line 225); includes the belief that the best way to prevent breast cancer is by self breast exams (#111112, lines 230-231); includes the belief that it's important to see the doctor regularly (#3005, lines 5-7); includes women make sure they keep in contact with themselves (#25862, lines 32-33); includes mammograms are good (#14, lines 375-378); includes being assertive about breast cancer (#111114, lines 262-263); mammograms make a woman feel like she's doing something to prevent breast cancer (#111114, lines 269-271)]

Women believe that mammograms save one's life (#111112, line 289).

[Includes the beliefs that mammograms are efficient and helpful (#111112, lines 312-314); includes women "thank God" for mammograms (#111112, lines 390-391); includes mammograms provide support by letting a woman know she's okay (#111115, lines 434-436); includes mammograms prolong one's life (#93, lines 423-425); includes mammograms do a lot for a woman (#14501, line 273); includes it's a miracle when a mammogram comes back normal (#14501, lines 275-276)]

Women do not think mammograms do that much for them (#33953, line 243).

[Includes mammograms do nothing (#48, lines 391-392); includes mammograms are not important (#28, lines 309-311)]

Women think mammograms have flaws (#33953, lines 244-245).

[Includes hope/worry that they're accurate (#33953, lines 249-251); includes wonder if the test is sufficient (#33953, lines 280-281) and wonder if the test is true (#33953, lines 285-286); includes mammograms miss some of the lumps (#10943, lines 342-344)]

Women do not get mammograms because they do not think they will ever get breast cancer (#30903, lines 481-482).

[Includes doubt that a mammogram will find any problems (#93, lines 705-707); includes a lump has never been found by self exams so a mammogram is unnecessary (#19293, lines 180-183); includes a woman rarely gets sick so there's no need to get checked often (#10943, lines 553-555)]

### **Beliefs about breast cancer and cancer in general**

Women think cancer is a disease that eats, crushes, tears up a person from the inside (#200077, lines 16, 33-34).

[Includes fear of cancer eating one's body (#4, line 228); includes cells go crazy inside your body (#10943, lines 448-450); includes cancer attacks your body (#4, line 56); includes cancer is an ugly disease (#200077, lines 25-26); includes devastating (#4, line 22); includes cancer is a virus inside of oneself (#111112, lines 214-215)]

Women think that cancer means living or dying (#3005, line 12).  
[Includes the belief that cancer is always life threatening (#33953, lines 171-172); includes having breast cancer would make you feel as if your life is at its end (#4527, lines 405-408); includes cancer is deadly (#18389, lines 67, 71); includes cancer means finality and death (#93, line 36); includes breast cancer is a killer (#14, lines 304-305); includes life wouldn't be very long after having breast cancer (#221478, lines 122-123)]

Women associate breast cancer with deformity (#10943, line 47).  
[Includes mutilation (#23134, lines 181-182), being scarred and disfigured (#21478, line 42); includes breast cancer makes women think of being butchered (#18389, line 120)]

Women associate breast cancer with isolation (#111116, line 116).

Women associate breast cancer with survival (#16553, line 45).

Women think of breast checks when they think of breast cancer (#16553, line 55).

### **Beliefs about the causes of breast cancer**

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Women think having a bad attitude causes chemical changes in one's body, which can cause cancer (#10943, lines 176-179).

[Includes the belief that thinking a lot about getting sick can cause one to get sick (#10943, lines 270-272)]

Women believe cancer is stress related (#33953, lines 188-189).

[Includes not dealing with difficult situations in your life as they arise makes your body weak (#33953, lines 195-203)]

Women think that larger breasted women get breast cancer, as opposed to women with small breasts (#15868, lines 32-34).

[Includes having small breasts keeps you from getting breast cancer (#15868, lines 283-284)]

Women believe that having your breasts rubbed too hard can cause breast cancer (#15556, lines 583-585).

[Includes hard licks on one's breasts, rough mate, bumps (#15868, lines 304-309)]

Women think the Lord gives them breast cancer because they've been taking things for granted and haven't suffered enough in life (#15556, lines 615-623).

Women think there's a connection between susceptibility to breast cancer and breast-feeding (#14454, lines 304-306).

[Includes it's not good to dry up your milk instead of breast feeding your child (#14454, lines 308-310); includes there's a connection between breast feeding and a woman's organs resettling in the correct way after giving birth (#14454, lines 317-320); includes breast feeding is natural and what we don't know about it is hurting us (#14454, lines 321-322)]

Women believe they get breast cancer because they're born with the design to manifest breast cancer later in life (#200077, lines 112-115, 120-124).

[Includes you'll get cancer if you're supposed to (#4, lines 128-129), includes "we all get our dish" (#4, lines 123-124); includes destiny (#23134, lines 361-363)]

Women believe that no one is exempt from getting breast cancer, even if there is no family history of breast cancer (#111112, lines 174-179).

Women think breast cancer is more prevalent among white women because they rarely hear about black women with breast cancer (#48, lines 253-259).

[Includes the is never geared towards African American women (#48, lines 270-275); includes they do not feel they have to worry about breast cancer and mammograms because the media portrays breast cancer as a white woman's disease (#48, lines 311-314); includes women are unaware that it's important to have regular mammograms (#48, lines 344-346); includes women are not concerned about healthy breast tissue (#48, lines 367-368)]

Women believe there wouldn't be as much fear associated with breast cancer if it were more openly discussed (#4, lines 347-348).

[Includes there should be more sharing and talking among women about breast cancer (#4, lines 396-399); includes women think information about mammograms and breast cancer is kept in the dark (#4, lines 413-414); includes it's necessary to get the word out so women know about breast health (#23031, lines 66-67, 80-81); includes there aren't enough research studies being done (#14988, lines 92-93)]

### **Beliefs about cure and early diagnosis of breast cancer**

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Women believe that getting medical help is important if diagnosed with breast cancer (#111112, lines 96-99). [Includes the doctor is there to help you if you have breast cancer, you can't cure yourself (#111114, lines 67-69); includes seek medical attention if you find anything abnormal (#111112, lines 238-241)]

Women believe the early detection of cancer can prevent them from dying of cancer (#111112, lines 43-44).

[Includes the belief that breast cancer must be caught early (#33953, line 63); includes if caught early you have a chance to get help (#125rw, lines 177-179); includes belief that if breast cancer was in its early stages, you would be okay (#111113, lines 170-171); includes cancer is not a death sentence (#16553, lines 28-30)]

Women believe life goes on after breast cancer (#15868, lines 167-168).

Women believe that having surgery on cancer causes it to spread (#111115, lines 45-47).

[Includes when you have surgery the cancer gets worse (#111114, lines 39-41); includes if you have a biopsy, air can get into the cells and cause cancer to spread (#4, lines 72-76; includes the belief that you're taking a chance by having a biopsy and exposing the cancer to air (#4, lines 76-77); includes fear of getting a biopsy because of the air (#4, lines 169-171); includes a woman would not have treatment because it would cause the cancer to spread faster (#125mp, lines 116-118)]

Women believe a woman's success with beating breast cancer depends on her attitude (#33953, lines 101-102).

[Includes life philosophy (#33953, line 120); includes you have to be a fighter (#18389, lines 185-186); includes a woman has to be strong (#18389, lines 280-282); includes you have to have the will (#111114, lines 84-85); includes not giving up if diagnosed with breast cancer (#111113, line 237)]

Women believe that cancer treatment will either kill them or cure them (#33953, lines 323-324).

[Includes treatment is suffering (#33953, lines 321-323); includes the worst thing a woman can imagine if diagnosed with breast cancer is going through chemotherapy (#10943, line 403); includes women do not want to receive treatment for cancer if the treatment is going to cause more suffering (#33953, lines 324-326); includes fear of chemotherapy (#15556, lines 406, 414); includes chemotherapy does strange things to one's body (#15556, lines 423-425)]

Women think that if you can't afford treatment for breast cancer, you are going to die (#23031, lines 229-230).

### **Beliefs about preventing breast cancer**

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Women believe that exercise and eating healthy can keep them from getting breast cancer (#111112, line 207).

[Includes taking care of yourself (#3005, line 63); includes the belief that diseases result from lifestyle and eating habits (#33953, lines 175-176)]

Women believe there are things you can do to prevent cancer (#33953, line 31).

[Includes prevention is the cure (#25862, line 189); includes it's not necessary to get breast cancer (#30903, line 192)]

Women think there need to be more preventative measures for breast cancer (#111114, lines 367-368).

[Includes women need to be more educated about breast cancer (#111114, lines 368-369); includes every woman should see an educational video about breast cancer (#111114, lines 363-364); includes women need to know how to act right away if they notice a problem with their breasts (#14988, lines 93-97)]

Women think going for breast check-ups every year keeps them from getting breast cancer (#14988, lines 176-177).

### **Beliefs about breast removal**

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Women believe that breast cancer means losing a breast(s) (#200077, line 44).

[Includes the belief that if breast cancer is caught too late, a woman will lose her breast (#111112, lines 78-79)]

Women think losing a breast would make them less attractive (#200077, line 45).

[Includes worry that a woman will be seen by men as less attractive and that men will not desire her because her breast(s) is gone (#200077, lines 100-101, 103-105); includes a man may not "get over it" if he's with a woman who lost a breast (#111115, lines 309-310); spouses don't know how to respond (#44, lines 57-61); includes a woman would never get married if she lost a breast (#111116, lines 70-73); includes it would be hard to feel relaxed around men (#93, lines 347-348); includes losing a breast would make you feel less of a woman (#25862, lines 245-247); includes women don't know if they'll feel the same way about themselves if they have breast cancer (#15868, lines 218-219); includes breasts are what make you a woman (#111116, lines 144-145)]

Women believe the worst thing to happen if diagnosed with breast cancer would be to have their breast(s) removed (#200077, lines 213-216).

[Includes fear of breast removal (#3005, line 87)]

Women would feel embarrassed if they lost a breast due to breast cancer (#111115, line 302).

[Includes the belief that women wouldn't feel good about losing a breast (#111115, lines 308-309); includes feeling ashamed (#15868, lines 222-224); includes self-conscious (#23134, lines 213-214); includes shy (#93, line 333); includes worry about what other people will say about them if they only have one breast (#18389, lines 256-260); includes worry about being treated differently (#44, lines 55-56); includes fear of being taunted, laughed at (#93, line 353)]

Women would feel guilty and exploited if they lost a breast because of breast cancer (#93, lines 331-333).

Women would be okay with having their breast(s) removed if it meant saving their lives (#111112, lines 340-344).

[Includes the belief that if your breast gets cut off, you still have your life (#28, lines 86-87)]

Women no longer believe that having breast cancer means your breasts will be cut off (#28, lines 82-83).

Women believe that breasts are not the only things that make them women (#111113, lines 81-83).

[Includes losing a breast doesn't take away one's femininity or make one less of a woman (#111113, lines 148-149); includes you can still be the same person without breasts (#23134, lines 244-247)]